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We need to talk about dementia: The role of stigma and the social network in preventing help seeking for a diagnosis of dementia

Volume 1

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Declaration

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Abstract

Background: Worldwide it is estimated that over 50 million people are living with dementia but that up to 50% of people in high income countries and 95% of people in low and middle income countries have not received a formal diagnosis. There is an international drive to increase the number of people receiving a formal dementia diagnosis and for them to receive this diagnosis early in the disease process. In the UK around two thirds of people living with dementia have a formal diagnosis and initiatives in primary and secondary care have been aimed at increasing formal diagnosis rates. Research on the pathway to a dementia diagnosis reveals a complex, often lengthy process, in which a person with symptoms of dementia and their family make sense of what is happening and decide to seek help. However much less is known about the people who do not seek help and may remain without a formal diagnosis.

Aim: The overall aim of this study was to understand why people may not seek help for a diagnosis of dementia. This involved exploring the characteristics and experiences of a group of people who were not actively seeking help, but were identified to have undiagnosed dementia, following emergency admission to an acute hospital with a physical health problem.

Methods: This mixed methods study, set within a critical realist framework, had four phases – 1) a systematic review of 32 studies of the barriers and facilitators to help seeking for a dementia diagnosis from the perspective of carers and people living with dementia; 2) semi-structured interviews with 12 carers of people diagnosed with dementia during or following an acute hospital admission in the greater London area; 3) a retrospective cohort analysis of 1830 people referred to a memory clinic in inner London and; 4) an integration of findings from the first three phases.

Findings: The systematic review identified ten barrier themes and three facilitator themes. Multiple barriers compounded the delay to diagnosis and more than one facilitator was often required for help seeking to take place. An analysis of interviews with 12 carers of people diagnosed with dementia following an acute hospital admission, illustrated how carers created a 'bubble of normalisation' around themselves and the person living with dementia, to construct explanations that rejected a label of dementia and protect the person living with dementia from a loss of independence, discrimination and prejudice. There were missed opportunities to initiate help seeking and carers were fearful of talking about dementia. The diagnosis burst their bubble and left many feeling unsupported, still unable to talk about dementia and questioning the value of the diagnosis.

Analysis of referrals to a memory clinic revealed that people referred to the memory clinic by the acute hospital (people considered not to be actively seeking help for a diagnosis), were significantly more likely to be older and of white ethnicity than people referred by their GP. People diagnosed with dementia following referral from the acute hospital were more likely to have severe dementia, more likely to have died 12 months post referral and more likely to have had hospital admissions before and after referral. People referred by their GP were more likely to be diagnosed with cognitive impairment or be cognitively intact following their assessment.

In phase four the integration of data from the first three study phases resulted in five integrated themes: Fear of the label of dementia, alternative explanations, preserving autonomy, independence and the way of life, the potential of informal networks and the role of health care professionals. Following a process of abduction and retroduction a model depicting three social structures and generative mechanisms which had the power to prevent help seeking for a dementia diagnosis was presented. The model proposed that stigma related to dementia and the threat this posed to independence and autonomy could prevent help seeking when the carer's social network ties shared these views and the carer was unable to share their concerns with others.

Conclusion: This study provides a unique contribution to the research on the pathway to a dementia diagnosis as it explores the experiences of a group of people who were not actively seeking help for a diagnosis. The study highlights the role stigma plays in preventing help seeking and the importance of the social network as a mediating factor with the power to prevent or facilitate help seeking. These findings suggest that if a formal diagnosis early in the disease process is to be beneficial, the broader societal response to people living with dementia needs to be positive and inclusive, lending support to the growing focus on dementia friendly communities and a social citizenship approach to dementia care and support. The difficulties carers experienced in talking about dementia should be considered as an important opportunity for interventions that encourage and support open communication within social networks about dementia.

List of Abbreviations

AD – Alzheimer's Disease

ADI – Alzheimer's Disease International

BAME – Black, Asian, and Minority Ethnic

CMO – Context, mechanism, outcome

COREQ – Consolidated criteria for reporting qualitative research

CQUIN – Commissioning for Quality and Innovation

DBS – Demographic Batch Service

DSM – Diagnostic and Statistical Manual of Mental Disorders

GCP – Good Clinical Practice

GDPR – General Data Protection Regulations

GP – General Practitioner

HCP – Health Care Professional

HRA – Health Research Authority

IRAS – Integrated Research Application System

JDR – Join Dementia Research

LBD – Lewy Body Dementia

M - Mean

MMAT – Mixed method appraisal tool

MRI – Magnetic Resonance Imaging

NEM – Network Episode Model

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

NIHR – National Institute for Health Research

OECD – Organisation for Economic Cooperation and Development

PET – Positron Emission Tomography

PLWD – Person living with dementia/ people living with dementia

PPI – Patient and Public Involvement

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QUAL – Qualitative

QUAN - Quantitative

QOF – Quality and Outcomes Framework

R & D – Research and Development

SD – Standard Deviation

STROBE – Strengthening the reporting of observational studies in epidemiology

UK – United Kingdom

USA – United States of America

VaD – Vascular Dementia

WHO – World Health Organisation

Chapter 1: Introduction

Dementia is a progressive neurocognitive syndrome characterised by deterioration in memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (WHO, 2017). It is estimated that 885,000 people in the UK and over 50 million people worldwide are living with dementia and this is predicted to increase to 152 million by 2050 (Alzheimer's Disease International, 2019, Wittenberg et al 2019). The annual cost of dementia to the UK economy is £34.7bn and this is expected to rise to £94.1bn by 2040, with a higher cost to health and social care than cancer and chronic heart disease combined (Wittenberg et al 2019, Prince et al 2014).

Based on recorded dementia diagnosis data, 525,315 of the estimated 885,000 people in the UK living with dementia have a formal dementia diagnosis (Alzheimer's Research UK, 2020). Globally up to 50% of people in high income countries and up to 95% of people in low- and middle-income countries are also living with symptoms of dementia without a formal diagnosis (Prince et al 2016).

Interventions aimed at improving awareness of signs and symptoms of dementia amongst the general public and addressing factors associated with identification and diagnosis are key priorities in dementia policy worldwide and have been the focus of some UK research in recent years (Livingston et al 2017, Downs et al 2006a, Iliffe et al 2015). However, a review of these interventions found limited evidence of success (Mukadam et al 2015). Despite increasing numbers of people in the UK receiving a diagnosis of dementia, there remains a significant proportion of people without a formal diagnosis (Alzheimer's Research UK, 2020).

A UK taskforce on dementia research priorities recommended the need to understand why people may not wish to seek a dementia diagnosis and the consequences and unmet need for support that may result (Pickett et al 2018). Identifying people who do not seek help for a diagnosis is challenging. But people identified as having probable dementia at the time of an acute hospital admission, who have not sought help previously, may represent those in the population who are choosing not to seek help.

The aim of this critical realist, mixed method study was to understand the reasons why people may not seek help for a diagnosis of dementia. This chapter presents the background to the study including the focus on formal diagnosis rates, the timing of diagnosis, interventions to improve diagnosis rates in the UK and what is known about people identified to have dementia

on admission to hospital. The purpose and significance of the study will then be described, and the structure of the thesis will be outlined

1.1 Dementia diagnosis

A formal dementia diagnosis is usually made following reports that memory deficits leading to cognitive decline are affecting the usual activities of daily living of the person with symptoms. The diagnostic process will involve some level of neuropsychological testing, a history from the person and a key informant and tests to rule out alternative diagnoses e.g. imaging and blood tests (Prince et al 2011). The health system of each country will determine who makes a diagnosis, but it is most often made by specialist clinicians in memory clinics, by psychiatrists, geriatricians, neurologists or in primary care.

Dementia is considered a worldwide public health concern and dementia strategies and policies in many countries include an aim of improving formal diagnosis rates. In 2017 the World Health Organisation (WHO) set an ambitious target of formal diagnosis rates of 50% in a minimum of 50% of countries by 2025 (WHO, 2017). With considerable variation in diagnosis rates across the globe, for example estimates of 95% of people undiagnosed in Thailand (Jitapunkul et al 2009) and just under 60% in Denmark, some countries will find these targets easier to achieve than others (OECD, 2018). The target will also be difficult to verify as access to dementia diagnostic services and the standard of diagnostic data collected and monitored across the globe varies (OECD, 2018). The extent to which dementia is recognised as a medical problem also differs, as some languages do not have a word for dementia (Patterson, 2018). Improving diagnosis rates has become a key policy imperative in the UK, particularly since the publication of the Prime Minister's Challenge on Dementia (Department of Health, 2012). Although determining accurate national diagnosis rates is challenging, UK studies have shown a steady increase in the number of people receiving a formal diagnosis, with a 56% rise between 2010 and 2016 (Donegan et al 2017, Mukadam et al 2014, Alzheimer's Research UK, 2020). The current UK national dementia diagnosis rate is around 68%, leaving about a third of people undiagnosed (NHS Digital, 2019).

The aim of a formal diagnosis of dementia is so that "people with dementia and their family carers can receive the treatment, care and support following diagnosis that will enable them to live as well as possible with dementia" (Department of Health, 2009:17). A formal diagnosis is often a prerequisite for access to dementia specific services and interventions and although at present there is no cure or disease modifying therapy for dementia, there is evidence to

support some pharmacological and non-pharmacological interventions for people living with dementia (Prince et al 2011). An assessment for dementia is an opportunity to identify any treatable causes of cognitive impairment and to address any comorbid health conditions that may exacerbate dementia symptoms (Prince et al 2011). Following diagnosis, acetylcholinesterase inhibitors are drugs which can slow the progression of symptoms in some people living with dementia and are currently recommended by NICE (NICE, 2018) for people with Alzheimer's Disease (AD) and Lewy Body Dementia in the mild and moderate stages of the disease. There is also evidence from randomised controlled trials to suggest that non-pharmacological interventions such as cognitive stimulation and cognitive rehabilitation can produce short term improvements in cognitive function or reduce cognitive decline in the early stages of dementia (for example Bottino et al 2005, Clare et al 2010, Hanley et al 1981, Niu et al 2010, Requena et al 2006, Spector et al 2001, Onder et al 2005, Spector et al 2003, Wallis et al 1983). Other interventions such as support groups and physical activity interventions can improve quality of life and limit a reduction in activities of daily living (for example Logsdon et al 2010, Blankevoort et al 2010, Santana-Sosa et al 2008).

There is also evidence to suggest that supporting carers of people living with dementia with multi-component interventions including education, support and respite, can improve carer quality of life and delay institutionalisation of the person living with dementia (for example Schulz et al 2003, Burns et al 2003, Graff et al 2007, Chien and Lee 2008). Carers of people living with dementia play a key role in initiating assessment and diagnosis of dementia, often being the one who encourages a person with symptoms to seek help (Perry-Young et al 2018). As the disease progresses carers, usually an adult child or a spouse, take on an increasing role in supporting the person living with dementia in activities of daily living and decision making, often with a significant impact on their own quality of life, physical and mental wellbeing (Miller et al 2016, McCabe et al 2016).

There are considered to be a number of other benefits to receiving a formal diagnosis of dementia, although due to a paucity of research based evidence these tend to be based on expert opinion or on studies of small samples of people living with dementia (PLWD) and carers (Prince et al 2011, Dubois et al 2016). The possible benefits and harms arising from a diagnosis of dementia are summarised in Table 1.1. Without well designed trials the benefits of diagnosis may be exaggerated, however, there is also little research based evidence for the harms or disadvantages of diagnosis (De Lepeleire et al 2008, Brayne and Kelly 2019).

Studies using financial modelling suggest that there are also likely to be economic benefits to a diagnosis of dementia as well as personal benefits for the person diagnosed and their carer (Prince et al 2011). These include the impact of the introduction of memory services and carer interventions on delayed institutionalisation (Banerjee and Wittenberg 2009, Mittelman et al 2006).

Table 1.1 Possible Benefits and Harms to Having a Dementia Diagnosis

Possible Benefits to diagnosis	Possible harms to diagnosis
For PLWD • Right to know [1, 7, 13] • Confirmation of suspicions, relief, reduced uncertainty, and anxiety [1, 2, 3, 4, 5, 8, 12, 13] • Access to information and support [1, 3, 5, 6, 12] • Identification of treatable causes of cognitive decline [1, 6] • Access to pharmacological and psychosocial treatments [1, 3, 6, 7, 12, 13,] • Ability to plan, including legal, financial issues, advanced directives [1, 2, 3, 6, 13] • Risk reduction or crisis avoidance e.g. safety, driving [1, 3, 7] • Contribute to awareness raising and advocacy [1] • Ability to take part in research / clinical trials for new treatment or interventions [1] • Make lifestyle or home adaptations to maintain independence [1, 6] • Delayed institutionalisation [1, 13] • Promote involvement and shared management of care between	For PLWD • Right not to know [1, 13] • Diagnostic overshadowing or misdiagnosis [1, 5, 13] • Labelling and stigma leading to social isolation/ exclusion [1, 5, 8, 12, 13] • Reduced mental and emotional wellbeing including shock, distress, grief reaction, denial, uncertainty [1, 5, 8, 12] • Increased risk of suicide [9, 10] • Reduced autonomy [1] • Threat to selfhood, status, and loss of role [1, 8, 12, 13] • Fragmentation of relationships if others unable to cope [1] • Financial consequences and discrimination in the workplace [1] • Lack of post diagnosis support [1, 12, 13] • Insensitive disclosure of diagnosis with no signposting to support or advice [1]

doctor, person living with dementia, carer [3]	
For carers • Access to education and support interventions [1, 3, 5, 7, 13] • Access to carers assessment, respite, and benefits e.g. attendance allowance [1] • Ability to adapt to carer role, develop coping strategies, plan for the future, and make the most of time with the PLWD [2, 3, 5, 7, 11] • Confirmation of suspicions, reduced anxiety, relief [2, 4, 11, 12] • Involvement in care management [11]	For carers • Expectation of carer role and associated carer burden [1, 12, 13] • Uncertainty over future [11] • Stigma leading to social exclusion [1, 11, 13] • Lack of post diagnosis support [1, 11, 12]
For health care services • Improved care and discharge from acute hospital admission due to individual care planning [1] • Service and workload planning, staff training and resource allocation [1, 5] • Ability to establish a relationship with PLWD and carer and implement management plan [3]	For health care services • Shifting of resources from post diagnostic services to diagnosis services [1] • Increased pressure on services and budgets [5]

[1]Dementia Action Alliance, 2013, [2]Derksen et al 2006, [3] De Lepeleire et al 2008, [4] Carpenter et al, 2008, [5] Iliffe et al 2003, [6] Brooker et al 2014, [7] Leifer 2003, [8] Aminzadeh et al 2007, [9] Draper et al 2010, [10] Erlangsen et al 2008, [11] De Vugt and Verhey 2013, [12] Bunn et al 2012, [13] Milne 2010a

It is clear that more research is needed to support the proposed benefits of a dementia diagnosis and to determine who benefits most from certain interventions and when (Prince et al 2011). There are likely to be individual characteristics that determine how well a person living with dementia and their carer adjust to a diagnosis, it is also likely that the availability

and quality of post diagnostic support will be important to help them in this process, the absence of which could outweigh any benefits (De Vugt and Verhey, 2013). The potential harms of a diagnosis may not be directly related to the diagnosis itself, but to the quality of care and support the person living with dementia and carer receive post diagnosis. Threats to selfhood and identity, anxiety and relationship changes could all be minimised with the right support and the impact of stigma could be reduced with improved understanding and awareness of dementia in society (Dementia Action Alliance, 2013). The debate around the benefits and harms often relates to the timing of a diagnosis, with the call for an increase in formal diagnosis rates accompanied by the desire to make the diagnosis early in the disease process to maximise the advantages of proposed benefits.

1.2 The timing of a dementia diagnosis

Prince et al (2011) outline four time points for a possible dementia diagnosis but state there is currently no clear evidence for the point in the disease process at which a diagnosis is best made (see Fig 1.1).

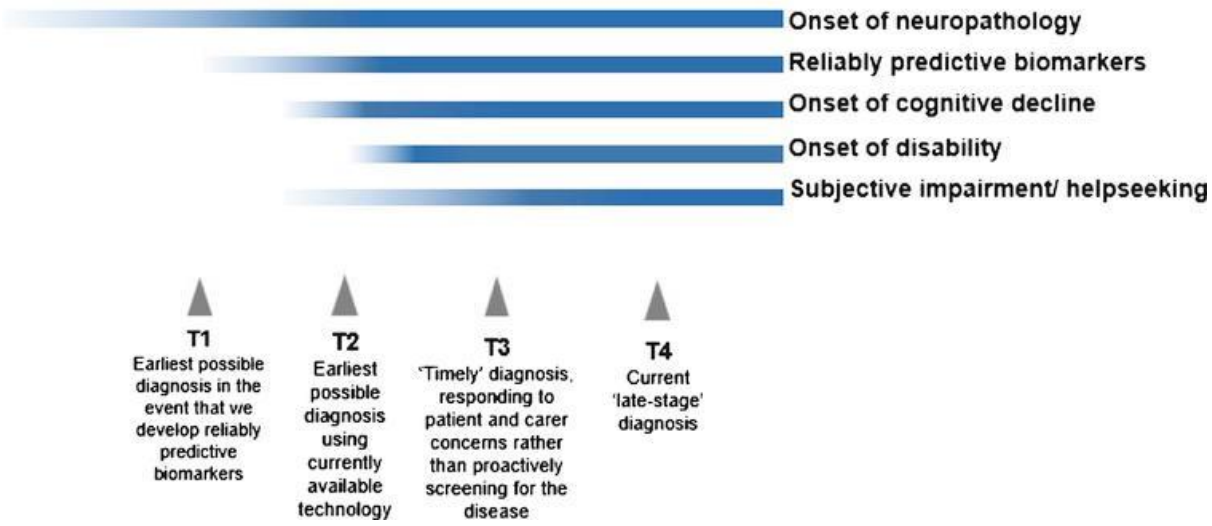


Figure 1.1 Timeline of disease progression from Prince et al (2011)

Diagnoses are most often made at a late stage (T4). There is no single definition of an 'early' diagnosis of dementia, but it could be described as one made at the earliest stage possible given current diagnostic technology (T2) or even earlier before symptoms develop, if reliable predictive biomarkers are found (T1) (Prince et al 2011). For a diagnosis at T1 or T2 to take

place, population or targeted screening would be necessary and these are not currently recommended in the UK (UK National Screening Committee, 2019). There are also potential dangers of a diagnosis at T1 or T2, when the person either has no clinical symptoms or could be at the stage of mild cognitive impairment. For those at T1, depending on their age, it is possible that they may not live long enough to develop symptoms of dementia and for those at T2 with mild cognitive impairment, they may never go on to develop dementia (de Vught & Verhey 2013, Prince et al 2011). Receiving a diagnosis of a disease that you do not currently have or may never have could result in any number of harms to the individual and their families, not least the increased risk of misdiagnosis (de Vught & Verhey 2013). Dubois et al (2016) argue that any benefit of diagnosis at these stages is dependent on the availability of a disease modifying therapy, which we currently do not have.

Increasingly the term 'timely diagnosis' is being used to replace the term 'early diagnosis', largely due to a recognition that 'early' could potentially mean at a pre-dementia, asymptomatic stage. Although it is also a reflection of a more person-centred focus on diagnosis (Watson et al 2018). Again there is no single definition of a 'timely diagnosis' but it has been described as one made "at the right time for that person"(Brunet et al 2012:1) or when the person or their family "express concerns and have a need for advice, treatment or support" (Prince et al 2011:5). But other definitions of a timely diagnosis refer to a time when symptoms are first noticed (Brooker et al 2014, De Lepeleire et al 2008) and within dementia policies and strategies the term 'timely diagnosis' is often used to mean a diagnosis made early in the disease process. Dhedi et al (2014) in a narrative study of general practitioner (GP) perspectives on the meaning of timeliness in dementia diagnosis, found that GP's saw themselves as fellow travellers in the journey towards a diagnosis with their patients, weighing up the unique factors of each individual and stressed that the "consequentiality of the diagnosis trumps the urgency of the diagnosis" (p6). This would fit with a definition of timely being 'at the right time for the person' and not one necessarily in the early stages of the disease.

A set of evidence based recommendations for a timely diagnosis of dementia aimed at policymakers across the European Union (ALCOVE) were produced in 2014 (Brooker et al 2014). These recommendations suggested that a timely diagnosis would be one at the point where people living with dementia and their carers could use the "information to make sense of what was happening to them, make lifestyle changes and plan for the future" (p686). They set four guiding principles or cornerstones of best practice for a timely diagnosis (Table 1.2), along with the actions that policy makers would need to implement these. There has been no

formal evaluation of the implementation of the recommendations, but a survey across five European countries, including Scotland, in 2018, revealed that almost half of carers felt that the diagnosis of dementia had not been 'timely' and wished the diagnosis had come earlier (Woods et al 2018). The most common factor cited as delaying diagnosis was reluctance of the person to be assessed, with other factors being a lack of awareness, health care professional (HCP) response and health system delays. However, the response of HCPs when concerns were first expressed had improved for more recent diagnoses, as had diagnostic disclosure practices, suggesting that improvements to the process of a timely diagnosis are being made.

Table 1.2 Principles of Timely Diagnosis (Brooker et al 2014)

Principle 1 Timely diagnosis of dementia should be available to all citizens who require it and accessible to all sections of the community at a stage when people first notice changes in cognitive function
Principle 2 Decreasing fear and stigma about dementia is a necessary precursor for increasing the numbers of people coming forward for diagnosis
Principle 3 The rights and wishes of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis
Principle 4 Giving and receiving a diagnosis of dementia is a key intervention in the complex adjustment process to living with dementia.

1.3 Interventions to improve diagnosis rates in the UK

A desire to improve diagnosis rates in England was first expressed in the National Dementia Strategy in 2009 (Department of Health, 2009), but specific targets for diagnosis were introduced following the Prime Minister's Challenge on Dementia in 2012 (Department of Health, 2012). The targets were aimed at primary and secondary care settings with financial incentives attached. Two financial incentive schemes focused on dementia were introduced in primary care between 2013-2016, in addition to dementia being part of the Quality and Outcomes Framework (QOF), a voluntary financial incentive scheme aimed at improving quality in primary care, since 2006 (Lui et al 2019). The aim of these incentives were to reward

GPs for assessing and identifying patients at risk of dementia and referring them to specialist services as required (Lui et al 2019). Other than improvements to primary care documentation there was no clear impact of these incentive schemes on dementia prevalence data (Iliffe and Wilcock, 2017). In 2013 an additional dementia financial incentive scheme was introduced in secondary care as part of the Commissioning for Quality and Innovation (CQUIN) (NHS Commissioning Board, 2012). The CQUIN required hospitals to carry out a cognitive assessment on all patients aged 75 and over who had an emergency or unplanned admission of 72 hours or more. The rationale was that those identified as potentially having dementia would be referred on to specialist services for further assessment and support. Although this particular CQUIN no longer exists, the requirement laid down by the CQUIN now forms part of the standard contract for NHS trusts in England.

The introduction of the incentive schemes for dementia in England were controversial with a substantial debate played out in the medical press (Brunet et al 2012). Although the schemes were proposed as a 'case-finding' approach, clinicians were concerned that these were not evidence based and amounted to screening programmes. Ranson et al (2018) in an examination of case finding approaches for the identification of dementia, defined case finding in this context as, "An offer of a brief, opportunistic investigation to identify possible signs or symptoms of dementia, initiated by a clinician during consultation with a patient at high risk of dementia on the basis of clinical judgement that an initial dementia enquiry is appropriate and is likely to benefit the patient." (p289). They concluded that the schemes in England were more comparable to screening than case finding, with other authors raising concern that the term 'case finding' was being used to justify screening (Wald and Morris 1996, McCartney 2014). As stated earlier, screening for dementia is not recommended in the UK based on a lack of clear evidence for the benefit of a diagnosis, the low specificity of the best available screening test and a lack of treatment to slow or prevent the disease (Brayne and Kelly, 2019). It is also suggested that the disease trajectory in people identified by intense case finding may differ from those who actively seek help (Brayne and Kelly, 2019). However the acute hospital admission has been identified as an opportunity to recognise undiagnosed dementia in a population who have not sought help in primary care (Russ et al 2012).

There has been very little research on the impact of the dementia CQUIN, with The Cascade Study in the East of England being the only study to date that has aimed to evaluate the scheme (Burn et al 2018, 2019). Burn et al (2018) conducted interviews and focus groups with staff in 12 acute hospitals and related primary care staff. They concluded that there was variation in how the scheme had been implemented, with no consistent pathway for patients

identified post discharge and poor communication between secondary and primary care. Although secondary care staff viewed the scheme more positively than primary care staff, there was a concern about the lack of appropriate post diagnosis support available and the potential of raising patient's expectations of help. Interviews with patients identified via case finding in two acute hospitals found that not only were patients and carers often unaware that assessments had taken place, follow up for further investigation of memory problems did not necessarily happen (Burn et al 2019). Subsequently the authors recommended that further research was needed to evaluate both the cost implications and outcomes for patients identified by case-finding approaches (Burn et al 2018, 2019).

In addition to these nationwide government schemes, smaller initiatives have been trialled to determine whether education and awareness amongst GPs and the public can increase diagnosis rates with mixed results. Two randomised controlled trials of educational interventions and a decision support tool for GPs, were carried out before the introduction of primary care incentives for dementia diagnosis. One resulted in an increase in detection of people living with dementia, but no change in diagnostic or dementia management practice (Downs, 2006a), the other concluded that the educational intervention did not have an impact on dementia case management or identification (Iliffe et al 2015). A more recent intervention study in which a personalised letter and leaflet about memory problems were sent from GPs to patients aged over 70 years, encouraging them to seek help, resulted in an increase in people presenting to their GP, but no increase in diagnosis rates (Livingston et al 2017). The authors consider the increase in presentation could have been from the 'worried well' but also that GPs may have not referred people for assessment over concern about waiting times and a lack of post diagnostic support. They suggested that future interventions need to target both the general population and HCPs. Outside of the UK, there are other interventions to increase patient engagement in dementia diagnosis that are currently the subject of a large European project and these interventions may increase our knowledge as to how a timely diagnosis can be encouraged (Rodriguez-Gomez et al 2019). But seeking help and receiving a diagnosis of dementia is clearly a complex process which requires further research and exploration.

1.4 Dementia in the acute hospital

It is estimated that at any one time a typical 500 bed general hospital in the UK will have at least 70 inpatients with undiagnosed dementia (Jackson et al 2017). Studies of people with undiagnosed dementia in acute hospitals have been limited to prevalence studies, but in the UK and Ireland these suggest that undiagnosed dementia can be present in up to 50% of

people identified to have a cognitive impairment on admission to hospital (Sampson et al 2009, Jackson et al 2016, Briggs et al 2017). People with undiagnosed dementia have been recognised as older and frailer than those with a recognised dementia diagnosis on admission to hospital (Jackson et al 2016). Consequently, they are a population that may benefit from a case finding approach, but little is known about why people may not have sought help before their admission to hospital.

1.5 Significance of the study

Despite increases in diagnosis rates, there are significant numbers of people in the UK and globally without a formal diagnosis of dementia. There is an international drive to increase the number of people receiving a formal dementia diagnosis and for them to receive this diagnosis early in the disease process. However, interventions aimed at increasing awareness and diagnosis rates have had limited success or been deemed controversial. For future interventions to be acceptable and successfully improve formal diagnosis rates, it is essential that we understand why people do not want to seek help and to determine how those people who do seek help might differ from those who do not.

Help seeking for symptoms of dementia is a complex process that is not yet fully understood and one in which carers of people living with dementia play a key role. If we are to support people to seek a formal diagnosis, understanding the role and experiences of carers in the help seeking process is essential. More importantly understanding the experiences of carers of people with dementia who have not actively sought a diagnosis will help to determine under what circumstances they may wish to seek help. Alternatively, if we are to respect those who do not want a formal diagnosis, understanding the support needs they have will help people with dementia and their carers to live well, with or without a diagnosis.

As the following chapter will show there is no ideal model to explain help seeking behaviour for a dementia diagnosis and research using theoretical models is limited. Consequently this study did not apply a theoretical model a priori and instead used a critical realist perspective to understand why people may not seek help for a diagnosis of dementia and then compared existing theory to the findings of the study in order to determine the underlying mechanisms preventing help seeking for a dementia diagnosis.

1.6 Aim of the study

The aim of this study was to understand why people may not seek help for a dementia diagnosis through four study phases:

1. A systematic literature review on the barriers and facilitators to help seeking for a dementia diagnosis from the perspective of people living with dementia and carers
2. A qualitative study to explore the experiences of carers of people diagnosed during or following an acute hospital admission who had not sought help previously in primary care.
3. A quantitative study to examine the characteristics of people referred to a memory clinic by their GP and people referred via case finding in the acute hospital.
4. An integration of the findings of the phases one to three to provide a fuller explanation of why people may not seek help for a dementia diagnosis

1.7 Structure of the thesis

This thesis describes a mixed methods study undertaken from a critical realist perspective. Chapter Two provides a background to the existing literature related to help seeking for a diagnosis of dementia.

Chapter Three describes the methods used for the four phases of the study. Chapters Four to Six are presented in the format of articles for publication. This format was chosen as a way to develop the researcher's skills in writing for publication and to ensure the timely publication of the study findings, thereby extending the reach of the evidence reported in this thesis. Chapter Four is the researcher's published systematic review of the barriers and facilitators to help seeking for diagnosis of dementia undertaken as phase one of study. In Chapters Five and Six the findings of the qualitative and quantitative phases of the study are presented respectively. These chapters are in the format of articles for publication and represent draft versions of the articles that will subsequently be published.

Chapter Seven is an integration of the findings of the systematic review, qualitative and quantitative study phases, which results in five integrated themes. These themes are then subjected to an abductive and retroductive analysis in Chapter Eight with the proposal of a model to demonstrate how help seeking for a dementia diagnosis is prevented.

Chapter Nine concludes this thesis with an overview of the study and the contribution the findings make to the existing body of evidence. A consideration of what this means for a timely diagnosis of dementia and recommendations for research, policy and practice are then made.

Chapter 2: Background

This chapter will provide a background to help seeking for a dementia diagnosis by examining key literature. A definition of help seeking and an overview of the types of research conducted to explore help seeking are provided. The existing literature related to the pathway to a diagnosis of dementia, research using health behaviour models to explore help seeking for dementia and research into barriers to help seeking for a dementia diagnosis are considered.

2.1 Help seeking

The terms 'help seeking' and 'health seeking behaviour' are often used interchangeably but have important conceptual differences. In a concept analysis of 'health seeking behaviour', Poortaghi et al (2015:7) defined the concept as "a behaviour through which a healthy individual intellectually makes a decision about his/ her health and also an endeavour to actively promote health through interaction with a health system". It is often used in the context of improving health through a change in behaviour, described as an active decision-making process involving interaction with the social network (Poortaghi et al 2015). Health seeking behaviour can be influenced by social, cultural and economic factors as well as disease pattern and health service factors and can result in health promotion, reduced risk of disease and the prediction of disease burden in the future (Poortaghi et al 2015). However, it may also result in outcomes similar to that of help seeking, including early diagnosis, treatment and management of complications (Poortaghi et al 2015).

The concept of 'help seeking' is related to action taken in response to a change in health status and the identification and appraisal of symptoms considered to be a problem (Cornally and McCarthy, 2011). It has similarities to the concept of illness behaviour, defined by Mechanic (Mechanic, 1995:1208) as the "varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilise various sources of informal and formal care". In keeping with health seeking behaviour, it involves intentional action and interpersonal interaction and a willingness to be open and share the concern (Cornally and McCarthy 2011). So, help seeking for a health concern can be defined as,

> "problem focused, planned behaviour, involving interpersonal interaction with a selected health care professional" (Cornally and McCarthy 2011:286).

For help seeking to occur an individual must be able to recognise and define the problem, make a decision to act and select a source of help (Cornally and McCarthy 2011). Once a source of help is selected the individual needs to have the ability and motivation to follow through their decision to act (Scott and Walter 2010). When considering help seeking for a diagnosis of dementia, this would mean that an individual needs to have an awareness of their symptoms and a recognition that this is a problem. It is well recognised that memory problems are often considered to be a normal part of the ageing process (Ross and Schryer 2014), and an lack of awareness of cognitive problems can be a neurological feature of early stage Alzheimer's disease, although this is not the case for all types of dementia and awareness is also likely to be influenced by psychosocial processes (Clare, 2003). However, help seeking for a diagnosis of dementia can often require a third party, usually a spouse or family member, to encourage a person to seek help or to initiate the help seeking process.

The consequences of help seeking will depend on both the type of help and source of help being sought. In Cornally and McCarthy's (2011) concept analysis, their definition related to formal help seeking, which can be described as "assistance from professionals who have a legitimate and recognised role in providing relevant advice, support, and/ or treatment" (Rickwood and Thomas 2012:175). But it is well recognised that people may first seek help informally, from friends and family, and increasingly from online media sources (Rickwood and Thomas 2012). Consequently, the outcome of help seeking will differ depending on whether formal or informal help seeking occurs. Informal sources are often consulted for recommendations for self-management, confirmation of symptoms, advice on whether the problem requires formal help, along with social permission and advice on how or where to formally seek help (Scott, 2007). As such the outcome may lead to formal help seeking, but if a person feels their problem is resolved, or that their symptoms have been invalidated they may not seek further help (Cornally and McCarthy 2011). Additionally, the type of help required such as, emotional or instrumental help, will influence both the source of help sought and the outcome (Cornally and McCarthy 2011). For the purpose of this thesis the definition of formal help seeking, as stated by Cornally and McCarthy (2011) above will be used.

2.2 Help seeking research

A delay in seeking help for a health problem, particularly one that is life threatening, transmissible or has a significant effect on function and quality of life has implications both for the individual and the health care system. This could include further transmission of a communicable disease, increasing severity of an illness and reduced efficacy of treatment (Scott 2007). Research designed to understand delays to diagnosis and treatment aim to identify factors which may be amenable to intervention and encourage earlier detection and presentation of symptoms and subsequently earlier treatment and improved prognosis (Scott et al 2013). In the context of dementia this already poses a dilemma, as without a cure or disease modifying therapy, earlier diagnosis does not necessarily result in an improved prognosis. Instead earlier diagnosis is promoted as a way to access information, advice and support in a timely manner (Prince et al 2011).

Research into help seeking behaviour is broad and can be fraught with methodological challenges, including a general lack of definition of the concept of help seeking (Scott and Walter 2010, White et al 2018). Studies generally fall into one or more types of research each with their own aims and challenges – 1) studies of pathways to diagnosis, 2) dispositional studies, 3) symptom appraisal studies and 4) studies of barriers and facilitators.

1) Studies of pathways to diagnosis aim to determine the steps taken on the pathway to a diagnosis for example, time intervals between first noticing symptoms and seeking help, and time from seeking help to diagnosis/ treatment, actions taken at each step and people consulted. However, there is often a lack of consensus in the terms used to denote steps on the pathway and the time intervals studied, with available conceptual models rarely used (Scott and Walter, 2010). These types of studies are usually retrospective, with the potential for recall bias, particularly for dates, when people have long delays to diagnosis or the symptoms of their disease make recall challenging (Scott and Walter, 2010). Data collection formats vary, with some better than others at identifying different types of data, for example dates (Scott and Walter 2010). As the depth and breadth of data collected varies and reasons for delay between steps are not always explored, a combination of methods could ensure optimum validity (Drebing et al 2004).
2) Studies with a dispositional approach aim to determine patterns of help seeking based on socio-demographic factors such as gender and ethnicity. However these offer a limited understanding of help seeking as they do not explain why such factors may delay help seeking and do not account for the dynamic nature of the help seeking process and contextual factors that may influence help seeking (Scott 2007).

3) Studies focused on symptom appraisal can be retrospective to determine how people who have been diagnosed appraised their symptoms or prospective where intentions to seek help in healthy samples, should they develop certain symptoms/ diseases, are explored. The use of theoretical models in these studies varies, with retrospective studies being largely atheoretical (Scott et al 2013, Werner et al 2014). Retrospective studies are subject to recall bias and assume knowledge of early symptoms in order to make symptom appraisals (Scott and Walter 2010). In prospective studies the intention to seek help may not always reflect actual help seeking behaviour although there is some evidence to suggest factors associated with the formation of intentions are associated with implementation, but the strength of association is weak (White et al 2018, Rickwood and Thomas 2012).
4) Research on barriers and facilitators to help seeking is usually retrospective with the same problems of recall bias that the other study types have. The depth and breadth of data collected in these studies varies, so the social or psychological context in which barriers exist is not always explored as they tend to focus on entry to health or diagnostic services so do not always capture attitudes towards diagnosis (Kasper 2000). The use of small qualitative samples in these studies may also overestimate the strength of some barriers or facilitators.

Although help seeking for a diagnosis of dementia has been less well studied than help seeking for mental health concerns or symptoms of cancer (Rickwood and Thomas 2012, Scott 2007), there is a considerable body of evidence that has resulted in several systematic reviews in the last decade. In Section 2.3 an overview of the reviews that focus on pathways to diagnosis including symptom appraisal and the research related to time to diagnosis in the UK is given. Social and psychological models of health seeking behaviour are often used to study help seeking and a number of these have been applied to help seeking for a diagnosis of dementia. Although some of these studies are included in recent reviews there is no detailed overview of how these have been applied to the study of dementia diagnosis and this is considered in section 2.4. The final section of this chapter gives an overview of the systematic reviews that focus on barriers to diagnosis from varying perspectives including people living with dementia, carers, health care professionals and different ethnic groups.

2.3 Pathways to dementia diagnosis

Studies of the pathway to a diagnosis of dementia vary considerably in the depth and breadth of data they collect. Most studies tend to be qualitative with interviews of small samples of carers and people living with dementia about their experiences from the onset of symptoms to formal diagnosis, and sometimes beyond. Rather than capture specific steps taken on the pathway to diagnosis, these studies seek to understand the pathway from a symptom appraisal and decision-making perspective. Three systematic reviews of qualitative studies on the pathway to dementia diagnosis have been undertaken in the last nine years (Perry-Young et al 2018, Rogers et al 2017, Mukadam et al 2011).

Perry-Young et al (2018) focused their review on how people living with dementia and carers experience and interpret early signs of dementia and make the decision to seek formal help. They reviewed nine studies including people living with dementia and carers, identifying the changes experienced, delaying factors, and advancing factors on the pathway to diagnosis. They concluded that early signs were experienced and interpreted differently by people living with dementia and carers resulting in a moral dilemma for carers, who may notice signs that the person living with dementia is unaware of or denies. Increasing signs and symptoms are interpreted in light of past events and knowledge and could be influenced by religious and cultural factors until there is recognition that help needs to be sought or a significant event occurs, for example a crisis or safety concern.

Rogers et al (2017) reviewed eleven studies, three of which were included in the Perry-Young et al (2018) review, to explore family member's experiences in the pre-diagnostic period. From their synthesis they describe a 'sense making process', similar to that of Perry-Young et al (2018), whereby family members notice and appraise changes in the person living with dementia until an accumulation of changes or a significant event results in seeking help. In the studies in Roger et al's synthesis, a family member almost always initiated the help seeking process and other people such as family and friends had an influence on this.

An earlier review by Mukadam et al (2011) focused on the pathway to diagnosis for people in minority ethnic groups. None of the studies included in this review were included in the subsequent reviews by Perry-Young et al (2018) and Rogers et al (2017) and although mainly qualitative, the 13 studies in the Mukadam et al (2011) review included three quantitative studies and four studies of lay public views on help seeking and dementia. Beliefs about the cause of symptoms influenced the likelihood of people seeking help, as did the reactions of

others, with stigma and a familial responsibility to care for the person living with dementia preventing help seeking. Some of the studies in this review were based on lay public views rather than the real experiences of people living with dementia and carers, but there are similarities in the findings of all three reviews.

Qualitative studies provide a deeper understanding of the experiences in the pre-diagnostic period and it is clear that people living with dementia and carers appraise symptoms over a period of time and the outcome of these appraisals are influenced by knowledge, cultural interpretations and other people in the lead up to seeking help. Perry-Young et al (2018) stress the likely importance of interpersonal factors in the help seeking process, although this tends to remain underexplored in most studies. Studies included in the reviews tend to have small samples and often report recruitment difficulties, but despite the different focus of each review, the fact that there is only a minimal overlap of studies, suggests that the evidence base to date has largely been included and this lends greater validity to the findings of the reviews. Rogers et al (2011) highlight the diversity of study samples, including people with different subtypes of dementia, varying age of onset of symptoms and different carer relationships to the person living with dementia and suggest this makes it difficult to determine if differences exist in the pathway to diagnosis depending on these factors, suggesting future research explores more homogenous samples. Recruiting more homogenous samples may be compounded though by the recruitment difficulties many studies report. The relatively small number of people living with dementia included in studies compared to carers and studies solely focusing on the view of carers, is also a limitation of findings. If we are to fully understand the experience of pathways to diagnosis for both the person living with dementia and carer, views of both needed to be explored equally (Mukadam et al 2011).

Two of the reviews highlight the need for improved public education about dementia and suggest that this may reduce the time taken to appraise symptoms and make a decision to seek help (Perry-Young et al 2018, Rogers et al 2017). Mukadam et al (2011) state the need for a greater understanding of the role played by ethnicity and culture in the help seeking process. The moral dilemma faced by carers who see a need to seek help but fear that this will be a betrayal to the person living with dementia is also highlighted as an area for further exploration (Perry-Young et al 2018). Along with this, understanding the carer's response in the pre-diagnosis period may help to understand future coping and the need for intervention to reduce carer burden in the future (Rogers et al 2017).

2.3.1 Time to diagnosis

In addition to the qualitative studies in the reviews above, other studies focusing on the pathway to a dementia diagnosis are quantitative and aim to determine the specific steps taken, for example people contacted and the time interval between these steps. Such studies allow a determination of where on the pathway delays occur and as such where interventions to reduce delay are needed. Although there are conceptual models designed to study pathways to care such as the General Model of Total Patient Delay (Andersen, 1995) and the Model of Pathways to Treatment (Scott et al 2013), to the researcher's knowledge neither of these models have been applied to the dementia diagnosis pathway. Most studies use structured questionnaires or interviews designed by the authors to gather data on the variables of interest to them. The only study to use a standardised, validated tool has been the Volpe et al (2019) study, who used the WHO encounter form, initially designed to study pathways to care in mental health services and adapted for the pathway to dementia diagnosis for their study.

The few UK studies that have focused on the steps and time intervals on the pathway to a diagnosis of dementia have had variable results. The two earliest studies focused on people diagnosed with early onset dementia, with Newens et al (1994) reporting that analysis of the hospital records of 186 people showed that around 76% of people were diagnosed within two years of symptom onset. A further study found that 60% of a sample 112 people in Leeds had sought medical help with 12 months of symptom onset, just under 20% between one to two years and 10% after two to three years (Williams et al 2001). The difference in measurement between these two studies demonstrates a fundamental limitation of pathway studies such as these. The studies measure different time intervals -symptom onset to diagnosis vs symptom onset to seeking help, making comparisons between studies difficult and without a breakdown of steps within the pathway it is not possible to determine where the greatest delays occur.

A study of 23 people with late onset dementia presenting to a UK memory clinic, found a similar time to diagnosis of that in the Newens et al (1994) study, with a mean time of 26 months from onset of symptoms to diagnosis in 2000 (Husband, 2000). Two international studies around the same time included UK samples and sought to compare times to diagnosis between countries (Wilkinson et al 2004, Bond et al 2005), although again their time measurements differed. In a sample of 91 UK carers, the average length of time between first noticing symptoms and the first doctor's appointment was three months, in one study (Wilkinson et al 2004). However, in the other study, in a sample of around 100 UK carers, the

average time from the carer first noticing symptoms to diagnosis was 32 months (Bond et al 2005). It is possible that some of the variation in the Bond et al (2005) study can be accounted for in the time taken for referral and waiting times to a memory clinic for diagnosis, although the 29 month variation is quite considerable.

If the greatest delay does occur between seeking help and diagnosis then studies that have taken place since the introduction of the National Dementia Strategy (Department of Health 2009) and subsequent incentives to improve the diagnostic referral pathway in the UK should be able to demonstrate a shorter time between symptom onset and diagnosis (Lui et al 2019, NHS Commissioning Board, 2012). However there have been few studies reported since then, most taking place around the time these incentives were introduced. One international study including a sample of 50 UK carers, reported an average time from first noticing symptoms to diagnosis, as around 11 months (Jones, 2010). However, in a study of 49 carers and 31 patients, attending a memory clinic in the North East of England the overall time from first noticing symptoms to assessment in the memory clinic was around 36 months, similar to that of Bond et al's (2005) earlier study (Chrisp et al., 2011). This study also broke down the pathway into smaller intervals with an average time of 12 months from first noticing symptoms to first talking to friends or family (although for 75% of the sample this was under 12 months), an average of 15 months between first talking to friends or family and talking to a HCP and a total of 28 months from first noticing symptoms to contacting a HCP. The mean time from referral to arrival at the memory clinic was just over 5 weeks, suggesting that in this study the greatest delay occurred prior to seeking help from a health professional. The most recent study was another international study by Volpe et al (2019) who included a sample of 23 people diagnosed with dementia, presenting at a Manchester memory clinic. The mean time between the onset of symptoms to first contact with a HCP was around eight months, considerably shorter than that in the Chrisp et al (2011) study, with around another 12 months between first contact with a HCP and memory clinic attendance, again suggesting the greatest delay comes after seeking help.

The lack of consistency in using standardised tools or models to study the pathway to diagnosis make studies such as these difficult to compare (Scott and Walter 2010). The relatively small samples from diverse areas of the UK studied over the last 20 years make it difficult to determine if the time to diagnosis in the UK is improving. Repeated studies of either large UK samples or specific geographical areas over time will be the only way to determine this. There may also be considerable variations in time to diagnosis depending who is asked to provide the data – the person living with dementia or carer. As the review by Perry-Young et al (2018)

suggests, early symptoms are interpreted differently by the person living with dementia and their carer and as such the time reported for symptom onset may vary. It is also difficult to determine where the greatest delay occurs, before or after seeking help, and this has important implications for targeted interventions to improve the timing of diagnosis.

2.4 Research using health seeking behaviour models to study help seeking for dementia diagnosis

In keeping with the concept of health seeking behaviour described in section 2.1, a plethora of models of health seeking behaviour or health behaviour change have developed across diverse academic fields in the last 50 years, although those focused on individual behaviour change are found predominantly in psychology (Davis et al 2015). Such models seek to explain behaviour and predict which factors under certain conditions precipitate behaviour change, with the aim of guiding interventions to modify certain factors to achieve desired behaviour to improve health (Glanz et al 2008). Despite the conceptual differences between health seeking and help seeking behaviour, health seeking behaviour models have been applied to the study of help seeking and most of these studies focus on help seeking intentions. Although there is a difference between an intention to seek help and the act of seeking help, it is considered that by understanding intentions, interventions which support what White et al (2018) describe as a 'foundation for help seeking', can be implemented, so that help seeking does take place when a future need arises (White et al 2018).

There are a wide range of health behaviour models, although a 2015 scoping review found that only four out of 82 theories of health behaviour change were applied in 63% of the 174 articles included in the review (Davis et al 2015). The authors of the review suggested that rather than these four models being of better quality or having a stronger evidence base than other models, they may have been chosen because of popularity or familiarity and as such there may be models of a better fit for some studies that are overlooked (Davis et al 2015). A limited number of models have been applied to the study of help seeking for a dementia diagnosis and it is likely that there are other models that would add a greater understanding to the help seeking process that have yet to be used. Some studies have used the models as a framework to analyse qualitative interview data with carers to determine which factors influenced their help seeking processes (e.g. Hughes et al 2009). Other studies use a model to study help seeking intentions in lay public samples exposed to vignettes describing people with symptoms of dementia, to determine which factors are statistically associated with an intention to seek help (e.g. Werner, 2003).

The six models applied to help seeking for a dementia diagnosis and the behavioural constructs studied in each model can be found in Table 2.2., with an overview of how each model has been applied in the sections that follow. The models used can be classified into three broad types – expectancy value models, dual process theories and stage theories (White et al 2018). Expectancy value models propose that the motivation to carry out a specific behaviour comes from the subjective value placed on the consequences of the behaviour and the likelihood of these consequences happening (White et al 2018). Dual process theories consider that the reasoned pathway in expectancy value models is not the only influence on behaviour and that there is a second reactionary or emotional pathway that also plays a part (White et al 2018). In contrast, stage theories propose that motivation to carry out a specific behaviour develops over a series of stages with certain behaviours only happening in each stage (White et al 2018).

Table 2.2. Health behaviour models applied to help seeking for a dementia diagnosis

Model	Type of model	Behavioural constructs/components of the model	Relevant dementia help seeking studies
Health Belief Model (Rosenstock, 1974)	Expectancy value model	• Perceived susceptibility • Perceived severity • Perceived benefits • Perceived barriers • Cues to action • Self-efficacy/ health motivation	Wackerbarth and Johnson (2002) Werner (2003) Hodgson and Cutler (2004) Werner (2004) Hughes et al (2009) Sayegh and Knight (2013)
Theory of Planned Behaviour (Azjen, 1991)	Expectancy value model	• Attitude - beliefs about the outcome of the behaviour • Subjective norm - beliefs about whether others would approve of the behaviour • Perceived control - beliefs about barriers/ facilitators to the behaviour	Devoy and Simpson (2017) Hailstone et al (2017) Roche et al (2018)
The Common Sense Model of Illness	Dual process model	• Identity - perception and name of symptoms • Timeline - expected duration of symptoms	Hamilton-West et al (2010) Hurt et al (2012) Shinan-Altman and Werner (2017)

Representations (Leventhal et al 1984)		• Cyclical timeline - temporal changeability of the illness • Consequences - severity of symptoms • Cause - perceived cause • Controllability - perceived ability to control the illness • Coherence - extent to which they understand the illness • Emotional representations - how they feel about the illness	Gleason et al (2016)
Cognitive Impairment Response Model (Qualls et al 2015)	Dual process model	• Cognitive pathway: Knowledge - Symptom Identification – Attribution of Alzheimer's Disease • Emotional pathway: Knowledge – Symptom impact - Appraisals	Qualls et al (2015)
Kleinman's Health Care System Framework (Kleinman, 1978)	Not classified	Three social arenas of a health care system: • Popular • Professional • Folk Beliefs within each arena related to the aetiology, onset, pathophysiology, course and treatment of specific illnesses	Begum et al (2013)

Levkoff's Help Seeking Model (Levkoff et al 1988)	Stage model	• Stage 1 - Disease and symptom experience • Stage 2 - Symptom appraisal • Stage 3 – Decision to seek care • Stage 4 - Medical care contact • Stage 5 - Reporting symptoms	Levkoff et al (1999) Koehn et al (2012)

2.4.1 Health Belief Model

The Health Belief Model is one of the most widely used models of health behaviour and also the one most frequently used in relation to help seeking for a dementia diagnosis (Champion and Skinner 2008). The model proposes that a specific set of six health belief constructs (Table 2.2.) can explain and predict health behaviour and that subsequently education to modify these beliefs may result in a desired health behaviour change (Abraham and Sheeran, 2015). It is proposed that each construct can individually predict health behaviour outcomes. In some studies perceived susceptibility and severity are combined to represent perceived threat and perceived barriers and benefits are combined to represent behavioural evaluation, although this is considered an incorrect use of the model which could undermine findings as it does not allow an accurate determination of which construct predicts behaviour (Abraham and Sheeran 2015). The model, as applied to help seeking for a diagnosis of dementia, would suggest that an individual would seek help if they perceived the disease to be a threat (high susceptibility and severity), there were benefits and few barriers to help seeking, they were motivated and felt able to seek help for symptoms they felt required help seeking.

Three studies of dementia help seeking using the Health Belief Model have focused on people's intentions to seek help should they develop memory problems, although there is considerable inconsistency in the way the model has been used. Two studies applied the model to data collected from carers of people who had been diagnosed with dementia (Hughes et al 2009, Wackerbarth & Johnson 2002).

Werner (2004) used four of the model's constructs to explore the perceptions of 79 people aged 55 years and older living in Israel, in relation to their willingness to seek help for memory problems. The interviews explored participant's beliefs about perceived susceptibility (cause of memory problems), perceived severity (consequences of memory problems) and barriers and benefits to help seeking, although the extent to which these related to their help seeking intentions was not examined. Some participants reported slowing of deterioration and improved well-being as benefits, others felt memory problems were inevitable and nothing could be done. Structural barriers such as cost and psychosocial barriers such as fear and stigma were reported as preventing help seeking and almost all participants reported that they would not seek help until their memory problems were severe enough to affect their daily functioning.

Wackerbarth and Johnson (2002) also refer to the model in the development of their postal survey of 528 carers in the USA, although participants were only asked to rate the extent to which 28 possible benefits and 31 barriers applied to them. The most frequently reported barriers were having a hard time accepting the family member's decline, worrying about how diagnosis would impact the carers life and worry about taking away driving privileges from the person living with dementia. The most frequently reported benefits were understanding the importance of making the most out of the present, getting treatment and medication for the person living with dementia and confirming there was a medical problem. Again, it is difficult to know the extent to which the barriers and benefits influenced their help seeking, carers did report a delay between first noticing symptoms and seeking help of 22.4 months on average, with 15.5% waiting over 37 months, but no connection was made by the study authors between the length of delay and extent to which carers reported barriers.

The Health Belief Model was used as a framework for semi-structured interviews with 17 African American carers, to explore the experiences that led them seek a diagnosis for their family member (Hughes et al 2009). All constructs of the model were explored with benefits and barriers to diagnosis and cues to action being the most helpful in understanding carer's help seeking decisions. They reported a lack of support from their social network and a dismissal of their concerns by primary care physicians as barriers to diagnosis. Benefits of diagnosis included confirmation of their suspicions, knowing what to expect and access to treatment. Carers reported the cognitive and behavioural signs that were a cue to them recognising that something was wrong. In contrast to Werner's (2004) study, perceived severity in Hughes et al's (2009) study was related to the cause and prognosis of Alzheimer's disease, with perceived susceptibility being related to carers beliefs that they may develop Alzheimer's disease. This was also the only study to include the self-efficacy construct of the health belief model, but this was related to the carer's ability to care for their family member, rather than the carer's ability to seek help, and the authors did not comment on whether it was felt to influence help seeking behaviour. It was not reported if there was a delay in seeking help and again it is difficult to know the extent to which their beliefs impacted on their help seeking decisions.

Two studies carried out statistical analyses to determine the association between constructs of the model and help seeking intentions. Werner (2003) used the findings of her study reported in 2004 to construct a structured questionnaire examining the factors associated with the intention to seek help for a cognitive examination in four hypothetical scenarios. In a sample of 186 people aged 53-90 years (mean 64.1 years), without memory problems living in Israel, only

two constructs of the model – perceived barriers and cues to action were significant predictors of an intention to seek help. Fewer perceived barriers and higher social influence, as a cue to action, were associated with an intention to seek help.

Hodgson and Cutler (2004) compared help seeking behaviour for personal concerns of developing Alzheimer's disease in a group of adults living with a parent with Alzheimer's disease and a comparison group without a parent with Alzheimer's disease. They focused on two constructs of the health belief model, perceived severity, and perceived susceptibility. Of the total sample, 68% had sought help from informal and/or formal sources for concerns about their memory. They found that higher perceived severity (those who worried more about their memory and those for whom others had mentioned changes in their memory) and higher perceived susceptibility (those with a parent with Alzheimer's disease) were associated with seeking help from informal and formal sources. Participants more likely to seek help also had greater knowledge of Alzheimer's disease, although the authors point out that it is not known whether this precipitated help seeking or that they gained the knowledge by seeking help, as around half of participants reported accessing information from libraries, the internet or Alzheimer's disease charities.

Following a review of the literature on differences in diagnostic presentation and barriers to dementia diagnosis among minority ethnic groups, Sayegh and Knight (2012) proposed an adapted version of the Health Belief Model. The Sociocultural Health Belief Model aims to take into consideration family centred cultural values, culturally associated beliefs and knowledge about dementia and acculturation as important factors that may influence help seeking for a dementia diagnosis. Although the model has subsequently been applied in relation to Alzheimer's disease literacy, cultural beliefs and perceived threat of Alzheimer's disease (Sun et al 2013), it has not been applied in relation to help seeking behaviour or intention to seek help in this researcher's knowledge.

The application of the Health Belief Model to help seeking for a dementia diagnosis is limited and as the discussion above demonstrates, its application is variable. It is helpful as a framework for understanding health beliefs related to dementia, but there does not appear to be consistency in the interpretation of the behavioural constructs in the studies described above, a criticism of the model generally (Abraham and Sheeran 2015). The model also does not allow for an understanding of the origin of health beliefs. Only two of the studies above sought to determine the associations between constructs of the model and help seeking, however their samples were quite different, and they did not measure all the constructs of the

model. Other criticisms of the model have been the possible interactions between constructs and the unknown extent to which they influence each other (Abraham and Sheeran 2015). Werner (2003) considered the static nature of a health decision assessed using the Health Belief Model as a possible limitation and the impact of past experience, emotions and the influence of others on health beliefs are not directly considered as part of the model (Abraham and Sheeran 2015).

2.4.2 The Theory of Planned Behaviour

The Theory of Planned Behaviour is another widely used, although often criticised model of health behaviour (Azjen, 2011). The model posits that the greater the intention to carry out a behaviour the more likely it will be to happen and that intentions are influenced by three constructs - attitude, subjective norm and perceived control (see Table 2.2.)(Montano and Kasprzyk 2008). In relation to help seeking for a diagnosis of dementia an intention to seek help is influenced by whether help seeking will have the desired outcome for the individual, whether other people would approve or disapprove of seeking help and whether there are factors facilitating help seeking or barriers to help seeking. The Theory of Planned Behaviour has been used in three studies of help seeking for a diagnosis of dementia to this researcher's knowledge, but it is considered to be a useful model in the study of help seeking intentions for mental health problems (White et al 2018).

Devoy and Simpson (2017) conducted focus groups with 22 adults without memory problems in Ireland to determine their attitudinal, normative and control beliefs related to help seeking for an early dementia diagnosis. The findings were subsequently used to construct a questionnaire to predict help seeking intentions in a sample of 95 adults. Thematic analysis of focus group data resulted in three themes of positive attitudinal beliefs towards help seeking – treatment to delay progression, planning for the future and increased social support and two themes of negative attitudinal beliefs – impact of diagnosis (including fear, shame, loss and coping with change) and a lack of options for treatment and care. Normative beliefs were related to the approval of others for seeking help and it was considered that family and peers would approve of help seeking and that younger and older adults would be less likely to approve. Control beliefs was classified as either barriers or facilitators to help seeking. Facilitators were family, friends and peers and the health care system, barriers were – fear, stigma, lack of education, accessibility of services and coping style. The findings of the quantitative survey of 95 adults, which measured knowledge of dementia in addition to the

components of the model, showed that both subjective norm (influence of family, friends, peers and health professionals) and knowledge predicted an intention to seek help.

Hailstone et al (2017) used a similar method to explore help seeking for a dementia diagnosis in people from South Asian backgrounds. Attitudinal, normative and control beliefs related to help seeking for a dementia diagnosis were determined through focus groups and interviews with 58 people of South Asian origin, along with a review of relevant literature. A questionnaire (APEND questionnaire) based on the three sets of beliefs and using a vignette of a South Asian older adult with memory problems was then completed by 51 participants. This was followed by statistical analysis of the association between beliefs and a willingness to seek help for themselves if they were to develop the symptoms described in the vignette. People who reported attitudinal beliefs that their GP would understand the cause of the problem and be able to provide treatment and information about services were more likely to consider seeking help, as were those who felt that others would expect or approve of help seeking (normative beliefs). People with normative beliefs that help seeking would be embarrassing were also less likely to believe that others would expect or approve of them seeking help. In addition, having control beliefs that help seeking would be easy to achieve and under the individual's control was associated with an intention to seek help. Hailstone et al (2017) also measured knowledge of dementia but in contrast to Devoy and Simpson's (2017) study, knowledge was not associated with attitudes predicting help seeking or with an intention to seek help.

The APEND questionnaire was subsequently used as part of a cluster randomised controlled trial to determine the feasibility and acceptability of a leaflet intervention to encourage help seeking for memory problems in Black UK adults (Roche et al 2018). Forty-seven Black adults with a mean age of 57 years, were randomised to receive either a generic leaflet about ageing well (control group) or a leaflet specifically designed to encourage help seeking for memory problems and the concerns that people of Black African and Caribbean populations may have about dementia (intervention group). Completing the APEND questionnaire two and four weeks after receiving the leaflets, items on the questionnaire suggested a favourable attitude to seeking help in both the control and intervention groups, with no differences between the two groups in their intention to seek help. These findings may support the findings of Hailstone et al (2017) that knowledge about dementia, in this case in the form of the intervention leaflet, is not necessarily associated with an intention to seek help.

It is difficult to appraise the usefulness of the Theory of Planned Behaviour based on three studies of help seeking for a dementia diagnosis. However, two studies report an association between subjective norm, in relation to whether others would approve of help seeking and an intention to seek help, suggesting this may be a significant factor worthy of further exploration. In comparison to other health behaviour models, the inclusion of normative beliefs in the Theory of Planned Behaviour has the potential to increase understanding about help seeking for a disease like dementia, where there is a known stigma attached, and the approval of others is likely to be important. A willingness to seek help or discuss concerns may be based on how others are perceived to view help seeking for the concern (White et al 2018). However, studies that focus on intention as the behavioural predictor have been criticised for the assumption that intention will always result in the behaviour under study (Armitage and Connor 2000). The studies described above measured participants' help seeking intentions for themselves, although two studies had samples comprised mainly of adults who may not have considered themselves to be at risk of developing dementia (Hailstone et al 2017, Devoy and Simpson et al 2017). Consequently, in these studies, asking about their intention to seek help for an older relative may have increased the validity of the findings (Hailstone et al 2017). A criticism of the Theory of Planned Behaviour has been that a focus on rational, reasoned behaviour does not account for the role of emotions and cognitive processes in the development of irrational beliefs which may influence behaviour (Azjen 2011). However, Azjen (2011) argues that there is no assumption in the model that beliefs are formed in a rational way and that emotions and affect may be background factors influencing behavioural, normative and control beliefs, although the model does allow for an understanding of the cause of beliefs.

2.4.3 Common Sense Model of Illness Representations

The Common Sense Model of Illness Representations (Leventhal et al 1984), also referred to as Leventhal's Self-regulatory model is a dual process model proposing two parallel processes, a cognitive process (what is the health threat) and an emotional process (how do I feel about it) which influence behaviour, such as help seeking (Hale et al 2007). The Common Sense Model suggests individuals use common sense when faced with an illness threat and base their illness representations on seven constructs (Table 2.2.)(Leventhal et al 2003). Illness representations are drawn from an individual's knowledge and past experience, as well as from other people, the media and health professionals and the process of self-regulation is recognised as a social one with cultural and social factors influencing illness representations by providing labels for

symptoms and influencing the interpretation of options for management of these symptoms (Leventhal et al 2003, Hurt et al 2012). It is also considered a dynamic model as illness representations are formed and changed over time (Shinan-Altman and Werner 2019).

Although the illness representations of dementia have been reasonably well studied, only four studies have sought to examine the relationship between illness representations and help seeking or intentions to seek help for a dementia diagnosis (Shinan-Altman and Werner 2019).

Hamilton-West et al (2010) randomly assigned 118 undergraduate psychology students to one of two vignettes describing a person with mild or moderate dementia, and asked them to complete an illness perceptions questionnaire indicating their help seeking intentions for the individual in the vignette. Those assigned to the mild vignette were more likely to identify the condition as dementia with more serious consequences and a longer timeline. The moderate vignette was more likely to be labelled as depression or stress. Although the label of dementia was positively associated with intentions to seek professional help there was no difference between the mild and moderate groups in their help seeking choices. Professional help seeking intentions were more likely when participants perceived the symptoms as severe and leading to serious consequences or permanent impairment and the authors suggest that it was the subjective perception of the symptoms rather than the objective nature of them that determined help seeking.

Help seeking was also related to the perception of symptoms as severe and having more serious consequences in a study of people with subjective memory complaints. Hurt et al (2012) interviewed 98 people using the Illness Perception Questionnaire for Memory Problems. Sixty of those interviewed had sought help via a memory clinic. The Common Sense Model constructs of identity and consequences were significantly different between the help seeking and non-help seeking groups. Those seeking help reported more symptoms, were more likely to attribute their memory problems to a biomedical cause and perceive more serious consequences. In addition, Hurt et al (2012) measured the component of social comparison which has not been included in any of the other dementia related studies using this model. Leventhal et al (2003) discuss the importance of social comparisons in self-regulation whereby individuals compare themselves to others either to determine their own level of risk of illness or to gain information about the trajectory of their illness. Although people tend to make downward comparisons by selecting individuals who are worse off than themselves, to make themselves feel better, rather than seek an accurate comparison. In Hurt et al's (2012) study those seeking help judged their memory problems to be worse than their

peers, despite there being no difference in memory assessment scores between the help seeking and non-help seeking groups.

In contrast, perceiving the consequences of Alzheimer's disease to be less severe was the only component of the Common Sense Model significantly associated with help seeking in a study of 236 lay people aged 50 years or older (Shinan-Altman and Werner 2017). The authors suggest that a perception of Alzheimer's disease as not serious may help individuals overcome any worry or stress associated with help seeking.

Consequences were also significantly associated with help seeking in another study (Gleason et al 2017). However, the author's interpretation of consequences in this study related to the consequences of seeking help rather than the consequences of having a memory problem. A sample of 187 lay African American participants (mean age 60 years), were given a description of mild cognitive impairment and then asked to complete a questionnaire measuring the cause, consequences (potential harms and benefits) and controllability components of the model and asked whether they would seek help from their doctor if they began to notice problems with their memory. Only the factors related to consequences were significantly associated with an intention to seek help. The anticipation of beneficial consequences of a timely diagnosis of mild cognitive impairment, for example preventing further decline, support from family, talking about and planning for the future and a belief that there was a low risk of harmful consequences, such as stigma, being perceived negatively by others, poor medical care and loss of insurance were associated with an intention to seek help.

As in the application of the previous models described, the use of the Common Sense Model in relation to help seeking for a dementia diagnosis is limited. None of these studies included carers of people living with dementia or people living with dementia, although understanding the illness representations and help seeking intentions of lay people may help to develop education and awareness programmes that increase timely help seeking (Shinan-Altman and Werner 2019). There was variability in the constructs of the model examined and although perceived consequences were consistently associated with help seeking, the nature of this association and its interpretation varied between studies. A further criticism of dementia related studies using the Common Sense Model are their cross-sectional methods, particularly as the model is considered to be a dynamic (Shinan-Altman and Werner 2019). With the exception of Hurt et al (2012), the studies discussed above related to help seeking intentions and those seeking help in Hurt et al's (2012) study were not subsequently diagnosed with dementia. Therefore, in order to understand whether the association between the

components of the Common Sense Model and help seeking still exist when an individual does have symptoms of the disease, an exploration of whether and how illness representations change over time and influence help seeking is needed.

2.4.4 Cognitive Impairment Response Model

Building on the parallel processes of cognitive and emotional representations of illness in the Common Sense Model, Qualls et al (2015) developed the Cognitive Impairment Response Model to predict help seeking for memory problems in a loved one. Qualls et al (2015) proposed that both cognitive and affective pathways influence the observation of symptoms and sought to understand how the interplay between these pathways influenced help seeking (Table 2.2). Their cognitive pathway proposed that basic knowledge of Alzheimer's Disease symptoms would allow an observer to identify a symptom and attribute it to Alzheimer's disease and that this attribution would lead to help seeking. Their emotional/ motivational pathway also started with a basic knowledge of Alzheimer's disease but required the observer to view the symptoms as having an impact, that is that they were different to 'normal', which then leads to an appraisal that the symptoms were concerning and seeking help is required.

To test the model 280 jury members in the US (mean age 40.74 years) were asked to read a vignette depicting their mother developing early memory and executive function problems and then complete a series of questionnaires to determine their Alzheimer's disease knowledge, symptom identification, appraisal, attribution and impact along with their help seeking intentions (Qualls et al 2015). The results showed that the strongest predictor of help seeking was both attributing the symptoms to Alzheimer's disease in the cognitive pathway and appraising the symptoms as a threat in the emotional/ motivational pathway. They also determined that although knowledge of Alzheimer's disease was the starting point for both cognitive and emotional pathways, this alone was not a strong predictor of help seeking. Symptoms needed to be recognised as Alzheimer's disease and be perceived as important. They also found that appraisal of risk in the emotional/motivational pathway was likely to influence the interpretation of symptoms in the cognitive pathway and that a stronger sense of threat had both direct and indirect influences on help seeking.

This would support findings of some studies using the Common Sense Model, where interpreting symptoms as severe was associated with help seeking and studies using the theory of planned behaviour, suggesting knowledge alone does not predict help seeking. Qualls et al (2015) recognise that the model needs to be tested further and to this researcher's

knowledge this has not yet been done. They also recognise that additional factors such as relationship structure and personal history may influence appraisal of symptoms in a family member.

2.4.5 Kleinman's Health Care System Framework

Kleinman (1978) developed a medical anthropological model called the Health Care Systems framework, which proposed that cultural systems, termed health care systems, govern health and illness beliefs and behaviours. Kleinman (1978) stated that, "The healthcare system articulates illness as a cultural idiom, linking beliefs about disease causation, the experience of symptoms, specific patterns of illness behaviour, decisions concerning treatment alternatives, actual therapeutic practices and evaluations of therapeutic outcomes." (p86). He described health care systems as consisting of three social arenas – the popular, professional and folk (non-professional healers) arenas. Most decisions related to when and where to seek help were made in the popular arena which consists of family, community and the social network. Within each of these arenas explanatory models exist which explain the aetiology, onset, pathophysiology, course, and treatment of specific illnesses and these may differ for the same illness between social arenas, causing conflict in health care transactions. Kleinman (1978) proposed that understanding and attempting to negotiate explanatory models could lead to improved adherence with medical regimes and appropriate help seeking.

Begum et al (2013) applied Kleinman's model in a qualitative study of 18 people with subjective memory complaints in the UK, half of whom had sought help via their GP and been referred to a memory clinic. All participants were formally assessed and only one was subsequently diagnosed with dementia. Begum et al (2013) used questions proposed by Kleinman (1980) to elicit explanatory models and proposed factors that impact on the likelihood of formal or informal help seeking. Those that had sought help had explanatory models that included biomedical causes of memory problems and were concerned about their memory. They also had positive views of health services (professional arena) and used opportunistic help seeking when visiting their GP for other problems or check-ups. Those who did not seek help had explanatory models that included psycho-social causes of memory problems and a lower level of concern. They sought help amongst family and friends (popular arena) and perceived their GP to be too busy or unlikely to take their concerns seriously. Begum et al (2013) concluded that, as proposed by Kleinman, people were more likely to seek help when the professional and popular explanatory model overlapped. They also suggested that those seeking help from within the popular sector may be less likely to seek professional

help as their explanatory models are reinforced by family and friends and their fears and concerns allayed.

This model considers the influence of the social network on health beliefs considerably more than the other models described. Although the Common Sense Model recognises this influence, it does not seek to determine where an individual's illness representations have come from and the Theory of Planned Behaviour only considers social network influence in relation to approval or expectation of help seeking. A lower level of concern about dementia was related to not seeking help in Begum et al's (2013) study which corresponds to higher levels of severity/ consequence being related to seeking help in other models such as the Health Belief Model and Common Sense Model.

2.4.6 Levkoff's Help Seeking Model

The final help seeking model to be applied to help seeking for a dementia diagnosis is Levkoff et al's (1988) stage model of help seeking. Levkoff et al (1988) proposed a model of help seeking for illness in older individuals that consisted of five stages (Table 2.2). As an older person moves through the stages, the normal ageing process may mask the early stages of disease (Stage 1), with symptoms attributed to ageing or other illnesses (Stage 2). The decision to seek care (Stage 3), is often precipitated by a 'cue to action' such as increased pain or reduced functional ability or the suggestion to seek help from a significant other. Even after the decision to seek care has been made the older person weighs up the benefits and barriers to accessing care (Stage 4) and decides whether to and how to express their symptoms (Stage 5). The model has been applied to help seeking for a diagnosis of dementia in two studies, although both studies only describe the first four stages.

The model was first applied to the help seeking of family caregivers of people with dementia in 1999 (Levkoff et al 1999) and specifically to the role of religion and ethnicity in help seeking. The findings of in-depth interviews with 40 carers from four different ethnic groups in the USA, described how they moved through the first four stages. The focus was on help seeking in general rather than for a diagnosis, but in Stage One carers expressed a broad range of symptoms that are generally accepted to be early signs of dementia. In Stage Two, African American and Irish American carers expressed a bio-medical model of attribution to explain the symptoms, whereby they recognised there was a problem which required medical attention. However, some Chinese American and Puerto Rican carers expressed a folk model of attribution to explain symptoms, attributing them to past traumatic experiences, although

this also included attributing the symptoms to normal ageing. Some carers used a combination of bio-medical and folk attributions to explain symptoms. The authors proposed that those using a bio-medical model of attribution may seek an earlier diagnosis than those using a folk model of attribution. They also suggested that using a mixed model of attribution 'may serve the adaptive purpose of providing caregivers and other family members options for deflecting social stigma associated with dementia (p343)'. The third and fourth stages were considered in relation to seeking help for care post diagnosis, with a decision to seek care influenced by safety concerns and family support and the need for culturally sensitive services when making contact with service providers.

Koehn et al (2012) used Levkoff's help seeking model to understand the experiences of Chinese Canadian carers and people living with dementia as they negotiate the pathway to a dementia diagnosis. Ten dyads consisting of the person living with dementia and their family carer were interviewed. In Stage One, carers reported more symptoms than the person living with dementia, with carers tending to report more behavioural symptoms and people living with dementia more memory loss symptoms. Symptom appraisal in Stage Two was described by the authors as an organic process with carers gradually recognising an accumulation of problems which would move them from normalising symptoms to the next stage of deciding to seek help. For others having knowledge of dementia or working in health care helped them to determine the nature of the symptoms and decide to seek help. In Stage Three the diagnosis for two participants was made following an admission to hospital but for the other participants a family member sought help to initiate a diagnosis. Over half of the participants experienced delays in diagnosis at Stage Four, because their family doctor dismissed their original concerns or focused on physical problems, with carers perceiving a reluctance from doctors to refer and diagnose dementia.

To this researcher's knowledge Levkoff et al's (1988) model has not been applied to help seeking for a dementia diagnosis in studies other than these two, neither of which included the fifth stage of symptom reporting. Therefore, it is difficult to determine its usefulness as a model to understand the help seeking process in this context. As in other models discussed, a stage model such as this can be useful to describe and understand the pathway to a diagnosis of dementia, but its use would be limited to those who have completed the pathway and received a diagnosis. There is some overlap of findings in Levkoff et al's (1999) study with Begum et al's (2013) study using the Kleinman's framework, as those with popular and folk explanatory models may be less likely to seek help, but this would need further study. Stage models have been criticised for their inflexibility, with the assumption that all individuals pass

through all stages of the model in a linear fashion (Pescosolido and Boyer 2010). It is also not clear from the Levkoff et al (1988) model what factors influence movement through the stages.

2.4.7 Summary of research using health behaviour models

As the overview above demonstrates there is considerable variability in the application of health behaviour models to the study of help seeking for a diagnosis of dementia. However the models do provide useful frameworks within which to understand help seeking for a dementia diagnosis with some consistent findings between models, such as beliefs about the consequences or severity of the disease influencing help seeking and a role for the social network and normative beliefs. Some of the studies also suggest that knowledge of dementia alone is not enough to facilitate help seeking, and this has important implications as interventions to improve timely diagnosis often focus on improving public knowledge and awareness.

A limitation of the research using health behaviour models such as these lies in the use of hypothetical scenarios and lay public samples to determine people's help seeking intentions. Few studies have applied the models to samples of people living with dementia or carers, and as such it is not possible to determine whether intentions to seek help would be realised when an individual develops symptoms of dementia. Intentions based on hypothetical scenarios do not take account of all the possible contextual factors that could influence a decision made in real time (Scott and Walter 2010). The use of questionnaires to elicit the perception and beliefs of participants allows for the study of larger samples and statistical analysis of the association between variables, but does not allow for an exploration of the origin of beliefs and how these influence help seeking. Similarly, the cross-sectional nature of these studies limits the understanding of health or illness behaviour as a longitudinal process, influenced by an individual's history, social context, social norms, and aspects of health services (Mechanic 1995).

A detailed comparison and critique of health behaviour models is beyond the scope of this overview and it is acknowledged that there may be other studies applying these models to help seeking for dementia diagnosis that the researcher has not identified. There are also likely to be other models that may be more applicable to understanding help seeking in dementia, which have not yet been applied to dementia studies. For example, models that have been used or specially developed to measure avoidance or delay in seeking medical help, such as

the Crisis Decision Theory (Taber et al 2014) and Judgment to Delay Model (Facione et al 2002).

The number of models applied to help seeking for a dementia diagnosis is small, with three of the six models only being used in one or two studies. The Health Belief Model, Theory of Planned Behaviour and Common Sense Model have all been applied to studies of help seeking intentions for mental health problems, and although none of these models were considered ideal, the Theory of Planned Behaviour was considered to be the only model which assessed all aspects of a definition of help seeking intentions in a review by White et al (2018). The Common Sense Model and Health Belief Model are both useful in understanding how people evaluate symptoms but do not address factors which may influence a willingness to seek help, such as the social network or subjective norms (White et al 2018). Help seeking has been described as a complex process that is part of an 'illness career' where symptoms are 'experienced, evaluated and managed' over a period of time (Wyke et al 2013:80). As such models used to understand the help seeking process need to be able to consider its complexity and Wyke et al (2013) suggest that this would be best achieved by integrating different models. They proposed an integrated framework of what they considered the best elements of the Illness Action Model (Dingwall, 2001), the Common Sense Model (Leventhal et al 1984) and the Network Episode Model (Pescosolido, 1991). The new integrated model incorporated the influence of knowledge, embodied experience, emotions, and social interactions (themselves influenced by culture and social structure) on the interpretation of, response to and evaluation of symptoms. However, the authors acknowledge that operationalising such a complex framework would be challenging (Wyke et al 2013). This does highlight though that existing models may not be ideal and the use of multiple models and a synthesis of their findings may be needed to better understand the help seeking process.

2.5 Barriers to help seeking for dementia diagnosis

Pathways to diagnosis studies and studies using health behaviour models often include barriers related to help seeking but there are many studies and some reviews that have focused specifically on identifying barriers and sometimes facilitators to a dementia diagnosis. An overview of these are now provided.

Bunn et al (2012) reviewed qualitative studies across the pathway to diagnosis and beyond to consider how people living with dementia and their carers both accommodated and then lived with a diagnosis of dementia. The pre-diagnosis period was described in the form of barriers to

early diagnosis and included findings from 27 of the 126 studies included in the synthesis. The main barriers to early diagnosis were a lack of awareness of signs and symptoms, normalisation of symptoms and stigma. Stigma was considered to be greater among minority ethnic populations, and family members were often the first to recognise symptoms and initiate help seeking. Some studies in the review reported barriers related to doctors who were slow to recognise symptoms or reluctant to make a diagnosis.

As the aim of the review was to determine psychosocial factors influencing experiences of dementia diagnosis and treatment rather than barriers to help seeking for a diagnosis, it is possible that relevant studies with other barriers were not included. Only two studies, one each from the reviews by Rogers et al (2017) and Mukadam et al (2011) were also included in the Bunn et al (2012) synthesis. However, there is consistency with the review by Mukadam et al (2011), which in addition to reviewing the pathway to care for people from minority ethnic backgrounds also reported on barriers to help seeking which included stigma. Mukadam et al (2011) also reported that concerns about autonomy of the person living with dementia, cultural expectations regarding familial care of the person living with dementia, negative experiences of health care services, language barriers, not knowing how or where to seek help and believing that nothing could be done were barriers to seeking help. Knowledge of dementia was the main facilitator to help seeking (Mukadam et al 2011).

Help seeking for dementia was the focus of a review by Werner et al (2014). The review included 48 studies which were a combination of help seeking for a diagnosis, help seeking for care post diagnosis and intentions to seek help amongst lay public samples. Of these, 20 studies reported barriers and facilitators to help seeking. Barriers reported by lay public samples included poor knowledge of dementia and socioeconomic factors such as low education, low income and belonging to a minority group. Stigma, a familial responsibility to care for the person living with dementia, and belief that dementia was part of normal ageing were reported as barriers in lay public and carer samples. Facilitators reported by carers were for care rather than diagnosis or were reported by lay public samples and included increased severity of the disease or increased carer burden.

In line with a focus on improving dementia diagnosis rates in primary care, particularly in the UK, four reviews in the last decade have sought to synthesise the research on barriers to diagnosis from a primary care physician perspective (Mansfield et al 2019, Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009). All of these reviews included studies related to diagnosis and the management of dementia post diagnosis, and included barriers related to

health care professionals and health care professional perspectives on the barriers encountered by people living with dementia and their carers. The number of studies included in the reviews ranged from 11 (Koch and Iliffe 2010) to 326 (Aminzadeh et al 2012). The number of studies reporting barriers to diagnosis in each review were 29, 11, 34 and 13 respectively (Bradford et al 2009, Koch and Iliffe 2010, Aminzadeh et al 2012, Mansfield et al 2019). Despite the reviews being conducted over a 10-year period, there was only minimal overlap in the included studies, with only five studies included in three or more of the reviews. This suggests there is a broad evidence base and lends greater validity in the consistency of findings between the reviews.

The barriers identified in the reviews were very similar and could be condensed to three themes, barriers related to the physician, barriers related to the health system and the barriers that physicians attributed to people living with dementia and carers. Physician related barriers and health system related barriers have been reported consistently over time (Mansfield et al 2019). Physician related barriers included a lack of confidence in diagnosing dementia, difficulty recognising early symptoms and worry about misdiagnosis, often attributed to a lack of training or education (Bradford et al 2009, Koch and Iliffe 2010, Mansfield et al 2019, Aminzadeh et al 2012). Physicians could also overlook the importance of dementia symptoms or prioritise physical problems (Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009). Some studies reported difficulties in disclosing or communicating a diagnosis to be a barrier (Koch and Iliffe 2010, Bradford et al 2009). Physician beliefs about dementia could also be a barrier, with studies reporting beliefs related to a lack of benefit to diagnosis and limited treatment options (Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009, Mansfield 2019). Concern about the effect of stigma on the person living with dementia and physicians own stigma related to dementia could also act as a barrier (Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009, Mansfield 2019). Barriers related to the health system included a lack of time during consultations and inadequate remuneration for physicians (Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009, Mansfield 2019). Concerns that diagnosis would put pressure on overstretched services (Aminzadeh et al 2012, Bradford et al 2009) and the lack of support for physicians to make a diagnosis, either in relation to secondary care service availability or guidance related to assessment tools to use in primary care, were also barriers (Koch and Iliffe 2010, Bradford et al 2009, Mansfield 2019). Some studies reported the lack of post diagnosis support for people living with dementia and carers as a barrier, but it was not always clear if this was a barrier to diagnosis or post diagnosis management (Koch and Iliffe 2010, Bradford et al 2009, Mansfield et al 2019).

Some studies report on physicians' perceptions of the barriers that result in delayed help seeking by people living with dementia and carers. Although the most recent review by Mansfield et al (2019) suggests that these tended to be included in studies before 2008, which may reflect an increase in studies exploring the experiences of people living with dementia and carers since then and a recognition that this will be a more accurate representation of their experience than the physician's perspective. Barriers reported in the reviews included denial and stigma, not noticing symptoms due to the prioritisation of physical problems, or compensation for cognitive problems and attribution of symptoms to normal ageing (Aminzadeh et al 2012, Koch and Iliffe 2010, Bradford et al 2009, Mansfield et al 2019).

Although there is some consistency in the barriers to diagnosis from the perspective of carers and people living with dementia, particularly the normalisation of symptoms and stigma, the reviews of these barriers from the perspective of people living with dementia and carers are limited and often do not aim to specifically identify barriers to diagnosis. There is greater consistency in the barriers to diagnosis related to primary care physicians, although the combination of diagnosis and management of dementia in these reviews may mean that some barriers may apply to one part of the pathway more than the other. On the surface many of the barriers in the reviews focused on primary care appear to be amenable to intervention. However, the structure and funding of primary care may itself be a barrier to this and attempts to address some barriers such as education and remuneration have not always had the impact on increased diagnosis that was hoped for (Chithiramohan et al 2019, Iliffe and Wilcock, 2017). Qualitative research has suggested the process of making a dementia diagnosis in primary care is less straightforward than the studies of barriers would suggest, with the process described as one which evolves over time as GPs "position themselves as fellow travellers in the patients challenging and unpredictable journey of becoming a person with dementia" (Dhedi et al 2014:7) and that GPs often find themselves working with a person living with dementia and their families in the pre-diagnosis period.

Research into barriers to diagnosis is popular and provides easy identification of potential targets for intervention in education, policy, and practice (Kasper 2000). However, the identification of barriers alone does not explain the complex psychological and social processes that may influence help seeking (Kasper 2000). Most studies focus on barriers to help seeking with few studies exploring facilitators to help seeking (Scott et al 2013). However, there could be important conceptual and methodological flaws in the sole focus on barriers. The presence of a barrier suggests that someone wishes to seek help or has tried to seek help and has been prevented from doing so (Scott et al 2013). Consequently, clear definitions of the concept of

barriers in relation to help seeking are needed, as factors related to delay in seeking help may better conceptualize those people who were not wishing to or trying to seek help. Research into barriers is also almost always conducted with participants who have, at some point, overcome the 'barrier' and sought help. Yet studies rarely focus on the factors that help people overcome barriers. Interventions to encourage help seeking may be more successful if they maximized the facilitators to help seeking in addition to removing the barriers.

2.6 Summary

This chapter has provided an overview of the diverse evidence base that exists for help seeking for a dementia diagnosis. Although the definition of help seeking as a concept appears straightforward, the actual process of help seeking is complex and multifaceted. Qualitative research on the pathway to dementia diagnosis reveals a process whereby people living with dementia and carers appraise symptoms in relation to their experience, knowledge, culture and the influence of others until they reach a point of seeking help. The timing and nature of this process is likely to vary between the person living with dementia and their carer, and more research is needed to explore the differences and similarities in these pathways to gain a fuller understanding of the process. A deeper exploration of the issues identified in systematic reviews is also needed, such as the interpersonal aspects of decision making, the moral dilemma experienced by carers, the impact of the pre-diagnosis period on subsequent carer coping and the role of culture and ethnicity. The time from first noticing symptoms to seeking help is clearly variable and research on time to diagnosis appears methodologically flawed. However, a better understanding of exactly where the greatest delays occur and if these differ between geographical areas or sub-types of dementia would help to ensure interventions aimed at improving timely diagnosis are focused at the right time point and in the right areas.

Research using health behaviour models have great potential in helping to understand the complex nature of help seeking and the social and psychological factors which influence it. However, one model alone is unlikely to achieve this, and a combination of the best fit models may be needed along with a synthesis of the findings of different studies to consolidate our understanding. Barriers to help seeking from a primary care physician perspective tend to be well described, although it is likely that these barriers do not accurately reflect the primary care dementia diagnostic pathway and more qualitative studies may be needed to understand this fully. Despite the number of studies which have explored barriers to help seeking for a dementia diagnosis from the perspective of carers and people living with dementia, these have only been reviewed superficially. A comprehensive review of the barriers to help seeking for a

diagnosis of dementia from the perspective of carers and people living with dementia is needed.

With the exception of studies of the intention to seek help, all other research on help seeking for a dementia diagnosis is conducted with people who have been diagnosed with dementia, so people who have, in some way, sought help for a diagnosis. Although understanding their experiences will give us much needed insight into the pre-diagnosis period it represents what Brossard and Carpentier (2017:11) refer to as a 'methodological bias', whereby research participants can only be accessed once they have reached the point of help seeking or diagnosis. This firstly assumes that diagnosis is a necessary point on the pathway that everyone should desire, and in the case of a disease like dementia, without a cure or disease modifying therapy, this could be contested. Secondly it does not help us to understand those who are yet seek help or overcome barriers to help seeking and as such their experiences may be different to those who do eventually seek help, in which case interventions to encourage help seeking may not impact on these people.

The thesis presented here aimed to address this methodological challenge by studying a group of people who did not actively seek help for a diagnosis of dementia, but received their diagnosis following identification of symptoms during an acute hospital admission. As is clear from the reviews of help seeking for a diagnosis of dementia described in this chapter, the role of a primary carer or family member is often crucial for help seeking to take place.

Chapter 3: Methodology

This chapter outlines the methodology used in this study. An outline of the overall aims and the mixed method design of the study is provided. This is followed by an explanation of the ontological and epistemological assumptions of critical realism, which underpin the work and how the choice of critical realism influenced the study design. The methods used to conduct the systematic review, qualitative and quantitative phases of the study are then described, along with any pertinent methodological and ethical issues followed by an outline of the methods for integrating the data from the first three phases.

3.1 Aims of the study

The overall aim of this study was to understand why people may not seek help for a diagnosis of dementia. This was achieved through a mixed method design which included four phases – a systematic review of the literature, a qualitative exploration, a quantitative exploration, and an integration of the findings from the first three phases (Table 3.1). The aim and associated research questions of each phase are outlined below in Table 3.1.

Table 3.1 Aims and research questions

Phase of study design	Aim (s)	Research question (s)
Phase 1: Systematic Review A systematic review of the barriers and facilitators to help seeking for a dementia diagnosis from the perspective of carers and people living with dementia	To identify barriers and facilitators to help seeking for a diagnosis of dementia from the perspective of carers and people living with dementia	What are the perceived barriers or reasons for a delay in help seeking and facilitators to help seeking to obtain a diagnosis of dementia from the perspective of people living with dementia and/ or their carers?
Phase 2: Qualitative exploration Semi-structured interviews with 12 carers of people diagnosed with dementia during or following an acute hospital admission in the greater London area	To explore the experience of carers of people diagnosed with dementia during or following a hospital admission to understand why they had not sought help beforehand	What factors influence help seeking for dementia related symptoms from the perspective of carers of people diagnosed with dementia during or following an acute hospital admission?

Phase 3: Quantitative exploration A retrospective cohort analysis of 1830 people referred to a memory clinic in inner London	To examine the characteristics of people referred to a memory clinic by their family doctor (help-seekers) or via the acute hospital (non-help seekers). To determine factors associated with receiving a diagnosis of dementia and survival following a diagnosis	What are the characteristics (e.g. age, gender, and ethnicity) of people referred to the memory clinic via different referral sources? How many people received a diagnosis of dementia and does this differ between referral sources? What sub-type and severity of dementia are people diagnosed with and does this differ between referral sources? Do the number of hospital admissions in the 12 months prior to referral and the proportion of people are still alive six/12 months post referral differ between referral sources? What are the factors associated with receiving a diagnosis of dementia? What are the factors associated with survival following a diagnosis of dementia?
Phase 4: Integration of findings An integration of the findings of the systematic review, qualitative exploration, and quantitative exploration	To provide a more complete understanding of why people may not seek help for a diagnosis of dementia	Why might people not seek help for a diagnosis of dementia?

3.2 Mixed Methods Design of the study

3.2.1 Rationale for using mixed methods

A mixed method design was incorporated into this study to address the complexity of the help seeking process and to provide a more complete understanding of why people may not seek help for a dementia diagnosis.

Definitions of mixed methods research have evolved from those focused solely on the mixing of methods (Greene et al, 1989), to include the process or methodology involved (Tashakkori et al, 1998) and then to wider definitions that include philosophical viewpoints (Johnson et al, 2007). Cresswell and Plano Clark (2018) advocate for diverse definitions of mixed methods and define the core characteristics of mixed methods research, stating that in conducting mixed methods research:

> "the researcher collects and analyses both qualitative and quantitative data rigorously in response to research questions and hypotheses; integrates (or mixes or combines) the two forms of data and their results; organises these procedures into specific research designs that provide logic and procedures for conducting the study and frames these procedures within theory and philosophy." (p5)

There are merits to conducting mixed methods research rather than using a quantitative or qualitative method alone, not least of which is the ability to offset the weaknesses of one method with the strengths of the other and vice versa (Plano Clark and Ivankova, 2016). But it is essential to justify the need for a mixed methods approach and provide a strong rationale for their use in a study. A widely used typology of five purposes for using mixed methods are – triangulation, complementarity, development, initiation, and expansion (Greene et al 1989). The rationale for the use of mixed methods in this study is complementarity. This is described as using qualitative and quantitative methods to:

> "measure overlapping but also different facets of a phenomenon, yielding an enriched and elaborated understanding of that phenomenon." (Greene et al 1989, p258)

The overall aim of this study was to understand why people may not seek help for a diagnosis of dementia. A mixed method systematic review was conducted to synthesise what is already known about the barriers and facilitators to seeking help for a dementia diagnosis. Exploring the lived experiences of people who do not seek help was best understood qualitatively, through interviews with carers of people diagnosed with dementia during or following an

acute hospital admission. But it was also important to determine whether those who did not actively seek help differed from those who did seek help and for this a quantitative analysis of data from a memory clinic database and hospital records allowed a comparison of the demographic and clinical characteristics of both groups. The systematic review, qualitative and quantitative phases of this doctoral study served to complement each other and it was intended that the integration of these three phases would allow a broader and deeper understanding of the factors preventing help seeking, than any one of these methods alone could do. There are disagreements in the literature as to whether the individual components of a mixed methods study should be able to stand alone or whether at least one component of the study should be incomplete without the others (Bazeley, 2015, Morse, 2015). Although the data from each phase of this study were analysed and written up separately for publication, the intention was always that the integration of the first three phases would contribute to a comprehensive understanding of help seeking for dementia diagnosis that went beyond the contribution of each individual phase.

3.2.2 Mixed method design

Mixed method design typologies have been widely discussed and developed in the literature (Cresswell & Plano Clark, 2018). The aim of these typologies are to describe the key components and design decisions of a study including the purpose or intent for mixing methods, the timing or sequencing of the qualitative and quantitative strands, the priority or weighting given to each strand and when and to what extent the strands are integrated. There are limitations to using design typologies as they can be interpreted as inflexible and not always appropriate for research problems where a study design evolves as the study progresses (Poth, 2018). As a result, more dynamic system based approaches, where the study phases interact and the design evolves over the course of the study, are starting to be used (Maxwell 2012, Poth 2018). A typology-based design is used to describe this study, however where the design deviated from that recommended by the typology the rationale for this is explained. The core decisions in relation to this study are described and shown in diagrammatic form in Figure 3.1.

Mixed Method design – The core design used in this study fits with the rationale of complementarity and is a convergent design (Cresswell & Plano Clark, 2018). The qualitative (interview) data and quantitative (memory clinic/patient record) data were collected and analysed separately using appropriate analytic techniques. The results were then integrated,

along with the findings of the systematic review, as described in the integration section below, with the intent of gaining a more complete understanding of the research problem.

Timing or sequencing of data collection – In this study the systematic review was conducted first, followed by phases two and three. In a convergent design collection of qualitative and quantitative data does not depend on the other, so data for each strand can be collected concurrently (Cresswell & Plano Clark, 2018). Although the start and finish of data collection and analysis for phase two and three of this study varied slightly due to practical considerations, such as ethical approval and recruitment of participants, the data collection and analysis overlapped.

Priority or importance of qualitative and quantitative phases – It is common for a notation system to be used to convey the relative priority or importance of qualitative (QUAL) and quantitative (QUAN) strands of a mixed method study, using upper case to denote the strand taking priority, along with a symbol denoting the sequencing of each strand (+ to denote a concurrent strand and → to denote a sequential strand) (Cresswell & Plano Clark, 2018). In this study the qualitative (QUAL) strand played a more prominent role in the study than the quantitative (quan) strand and is noted as *QUAL + quan*. It is more common for convergent designs to give equal priority to the qualitative and quantitative strands (Plano Clark & Ivankova, 2016, Cresswell & Plano Clark, 2018). However qualitatively driven mixed method studies allow the opportunity to make a strong qualitative case, with additional quantitative data which answers a significant question, that could not be addressed by a qualitative study alone (Morse, 2015). The qualitative interviews in this study yielded rich information about why people did not seek help and therefore played a prominent role in addressing the study aim. The quantitative data added to this by addressing whether demographic and clinical differences existed between people referred to the memory clinic from different sources.

Integration – In a convergent design with complementary mixed methods data the integration of the data is essential in ensuring the study truly reflects a mixed methods approach (Bazeley, 2018). The use of an overarching theoretical or conceptual framework is particularly useful to ensure that complementary data are integrated in a harmonised way and Bazeley (2018) suggests that critical realism can provide the flexibility needed when integrating varied data. A common method of integrating complementary data is juxtaposing results, where data from the different sources are presented side by side in a joint display so that they can be contrasted and compared (Bazeley, 2018). There are numerous ways to present data in a joint display and in this study the Pillar Integration Process developed by Johnson et al (2019) was

used to integrate and display the findings in a way which maximised the possibility of synthesis and interpretation. The integration of results is described and presented in Chapter Seven, after the separate presentation of the systematic review, quantitative and qualitative results in Chapters Four, Five and Six.

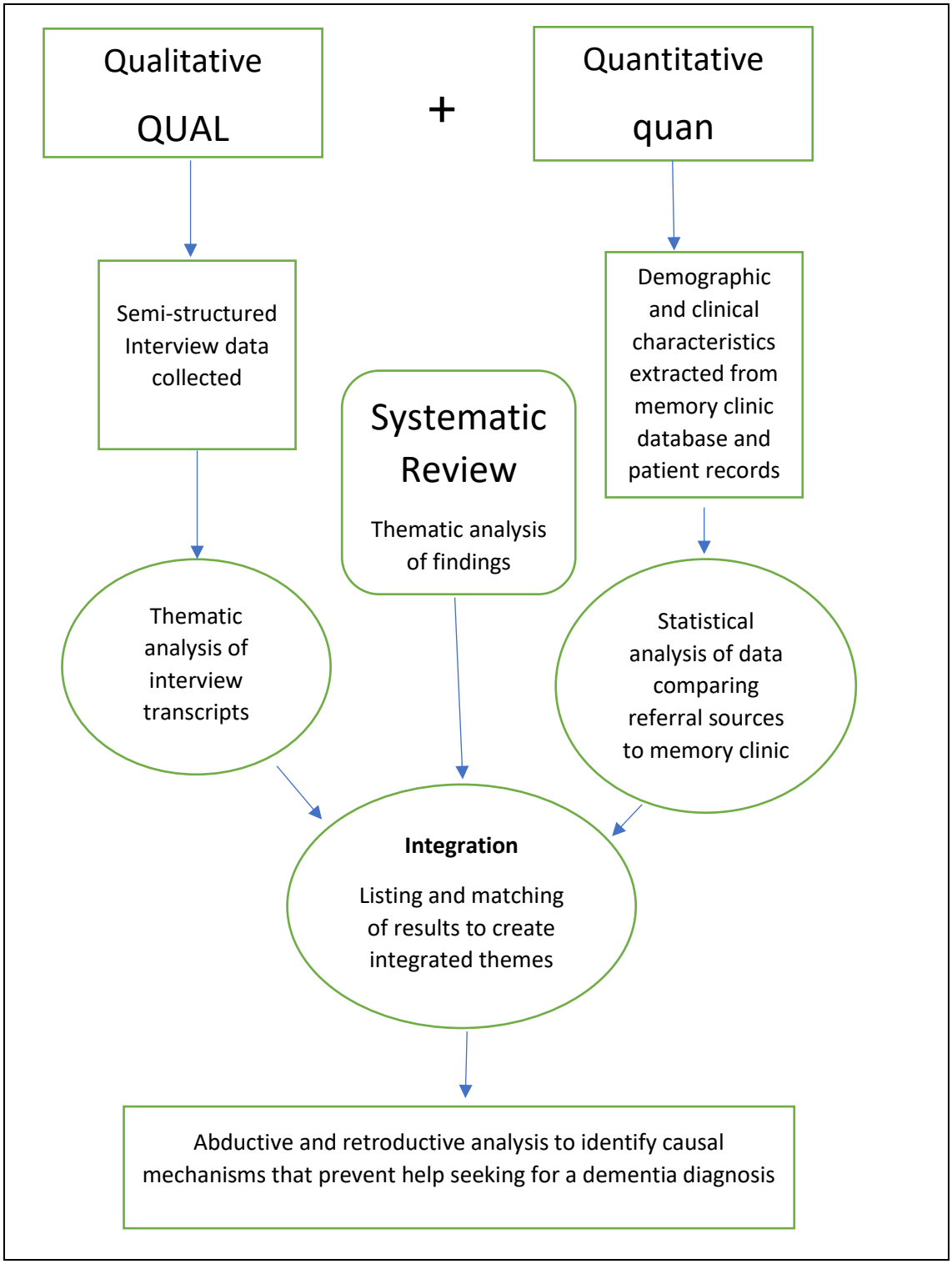


Figure 3.1 Diagram representing the convergent mixed method design of this study

3.3 Ontological and Epistemological assumptions

The philosophical assumptions underpinning this study are based on the meta-theory of critical realism. Although most closely related with the work of Roy Bhaskar, his critical realism was developed from the original work of Harré and has since been expanded and developed in the social sciences by Harré, Bhaskar and others (Blaikie and Priest, 2017). As such there are different versions of realism with varying underlying assumptions (Blaikie, 2017). It is important to state that the assumptions underpinning this study sit most closely with the early work of Bhaskar (1975, republished 2008). Critical realist approaches are often used in social science and organisational research, but as a meta-theory, critical realism does not prescribe the design or methods to be used to study social phenomenon (O'Mahoney and Vincent 2014). Instead critical realism provides "concepts which help create more accurate explanations of (social) phenomena than those which currently exist" (O'Mahoney and Vincent 2014:13). Consequently, there is diversity in the way critical realist studies are conducted. This section outlines the philosophical assumptions of critical realism and then describes how critical realism influenced the design and methods chosen for this study.

The ontological assumption of critical realism is that a reality exists that is independent of our knowledge of it. This is also considered the realist element of critical realism (Danermark et al 2019). The epistemological assumption of critical realism is that our knowledge of this reality can only be based on our own perceptions of it. Based on these assumptions Bhaskar (2008) makes a distinction between two dimensions of knowledge – the intransitive dimension and the transitive dimension. The intransitive dimension is the reality that exists independent of our knowledge and is made up of physical, natural, and social processes and phenomena. The transitive dimension is made up of the theories, models and facts we use to explain the intransitive dimension and is therefore always fallible and subject to change, although some explanations or theories may be more valid than others (Danermark et al 2019). To understand this further it is important to explain Bhaskar's (2008) version of reality.

3.3.1 The three domains of reality

Bhaskar (2008) describes reality as being differentiated into three domains – the real, the actual and the empirical. Figure 3.2 is a representation of the three domains and how they relate to each other.

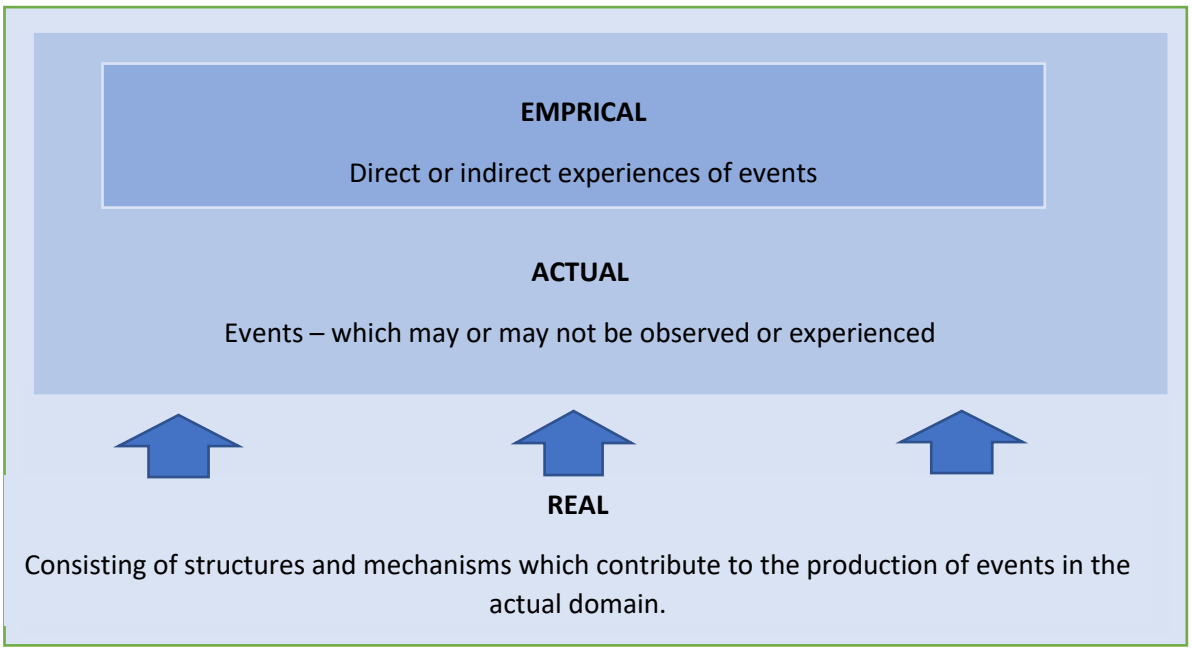


Fig 3.2 Bhaskar's three domains of reality

The *empirical domain* consists of our experiences of events and is therefore subjective and perspectival. But it is this domain we have access to as researchers.

The *actual domain* consists of events which we may or may not be aware of and may or may not be able to observe. It differs from the empirical domain, as what we observe in the world is not always the same as what actually happens (Danermark et al 2019).

The *real domain* consists of the structures and mechanisms that produce events in the actual domain, and which are experienced in the empirical domain. A description of how these structures and mechanisms, with their powers and tendencies, produce events is given in section 3.3.2.

Bhaskar (2008) refers to the 'epistemic fallacy' when science reduces what we know (the empirical domain) to what is really happening (the real domain). He suggests instead that science should aim to identify "relationships and non-relationships, respectively, between

what we experience, what actually happens, and the underlying mechanisms that produce events in the world" (Danermark et al 2019:25).

In addition to the three domains of reality, Bhaskar considers reality to be stratified (Bhaskar 2008). Structures and their mechanisms exist at multiple levels, and these levels are hierarchical. Danermark et al (2019) use the example of starting from the 'bottom up' with physical mechanisms in one level, chemical mechanisms in the next level, biological mechanisms in the next and so on with psychological and social mechanisms at the top, although economic, organisational, political and ideological mechanisms can also be considered as strata of reality. Each stratum of reality is formed by the powers and mechanisms of the strata below, but each new stratum is unique, with its own structures and mechanisms that cannot be reduced to the structures of the strata below it. Bhaskar uses the term emergence or structures having emergent properties to describe this (Danermark et al 2019). For example, water has properties that the same quantity of separate oxygen and hydrogen atoms do not, and teams can accomplish things that individual members could not (O'Mahoney and Vincent 2014). For this reason there are many potential levels of reality that a research problem may seek to determine the underlying causal mechanisms of and the decision to study a specific strata of reality will depend largely on the research problem itself. Although, it is important to be aware that different explanations for a phenomenon may exist depending on which strata of reality are studied. As the help seeking process for a diagnosis of dementia involves relationships and interactions between individuals, the person living with dementia and carer, person living with dementia or carer and health care professional, this study will focus on identifying the underlying mechanisms at the social level.

3.3.2 Causality

A successionist view of causation relies on the ability to predict outcomes based on the repeated observation of a sequence of events (Clark et al 2007). Critical realism presents an alternative, a generative view of causation which posits that objects with structures and powers have the ability to cause events, under specific social and cultural conditions (Blaikie and Priest, 2017). The real domain consists of structures and the powers they possess, which on a social level, can be described as "patterned arrangements in society such as norms and institutions" (Kontos et al 2010:120) and mechanisms described as "that which can cause something in the world to happen" (Danermark et al 2019:47). For the powers of a structure to cause change, a causal or generative mechanism must be triggered. Mechanisms can be of many different kinds including other social structures or the actions of individuals. The powers

of a structure may lie unexercised if a mechanism is not triggered and whether a mechanism is triggered, and the outcome it produces, will depend on the existing conditions or context. These are referred to as tendencies and Bhaskar describes society as an, "articulated ensemble of tendencies and powers which unlike natural ones, exist only as long as they… are being exercised" (Bhaskar 2011:42). Hence an event in the actual domain is the result of one or more mechanisms in the real domain being triggered and interacting, with the possibility of different outcomes resulting from the same structure depending on the context. This is possible because society is an open system, one which can be influenced by multiple factors, for example social, cultural, environmental, physical, historical, and geographical (Sayer, 2000). Whereas positivists would aim to control for such factors in experimental research designs when trying to determine causation, critical realists accept that open systems reflect the society in which events occur. This makes critical realism an ideal basis for studying complexity, particularly within health behaviour, as the health decisions people make are always context dependent.

Angus et al (2007) found that a critical realist perspective had particular relevance for the study of delays in breast cancer diagnosis, as the diagnostic pathway could be influenced by many factors. Similarly, Harwood and Clark (2012) in their study of decision making in home dialysis questioned how the continued low use of home dialysis could be adequately explained by an approach that assumes decisions are based on knowledge and rational choice, and that other causal mechanisms must be involved. This resonates with previous reviews of help seeking for a dementia diagnosis which have concluded that improved knowledge and awareness may lead to earlier help seeking (Perry-Young et al., 2018, Rogers et al., 2017). This study aims to gain a deeper understanding of the causal mechanisms at work.

Another element of the open system that makes a critical realist approach to studying health decisions appropriate, particularly at the social level, is the interplay between the structures in the real domain and human agency.

3.3.3 Structure and Agency

The real domain consists of structures and powers which, when causal mechanisms are triggered, produce events under certain conditions. However, these causal mechanisms always work through people's actions or through human agency (Angus et al 2007, Archer 2003). In critical realism, structure and agency are regarded as "distinct strata of reality, as bearers of

quite different properties and powers." (Archer 2003:2). Agency can be understood as the "capacity of an individual to act independently and to exercise choice" (Kontos et al 2010:120).

Structure has temporal priority over agency, as individuals are born into the structural contexts that were produced by agents before them (Archer 2003). Structures also have the power to constrain or enable the actions of agents (Archer 2003). But agents also have power, to determine how they are influenced by structures and to reproduce or transform social structures over time (Archer 2003). Through an 'internal conversation' agents determine their individual courses of action, and it is this interplay between structure and agency that is of interest in critical realist studies of health behaviour. In the study of delays in breast cancer diagnosis described above, Angus et al (2006) described how women's internal conversations may be influenced by social and cultural capital and personal understandings of breast cancer, but that these may not always be overt deliberations, where for example a gendered emphasis on family caregiving responsibilities leads women to automatically prioritise the needs of their family over themselves. In another critical realist study of the decision making of dementia support workers in a long term care setting, Kontos et al (2010) found that institutional policies and standards of care constrained their decision making and that through internal conversations the support workers sought to comply, negotiate or resist regulations in order to provide quality care. Examples such as these (Angus et al 2006, Kontos et al 2010) demonstrate the value of exploring social phenomena from a critical realist perspective, and specifically the role of structure and agency in the decisions carers make in the pre-diagnostic period which may influence help seeking for a diagnosis of dementia.

3.3.4 Critical realist study design

As stated previously, Bhaskar's critical realism is a meta -theory, so there are no prescribed ways in which a critical realist study should be conducted. Subsequently, a number of authors have set out to provide a guide to using critical realist ontology and epistemology in applied critical realist research, for example in explanatory social science research, qualitative research and realist evaluation (Danermark et al 2019, Maxwell 2012, Pawson and Tilley 1998).

Ackroyd and Karlsson (2014) describe applied critical realist study designs as varying along two continuums. The first is intensive versus extensive research. Intensive research can be equated with qualitative methods, and extensive research with quantitative methods and as such incorporates a wide range of possible study designs. But the key difference for critical realist

research between intensive and extensive designs is the extent to which the processes of abduction and retroduction are used (Ackroyd and Karlsson 2014).

All types of logic (inductive, deductive, abductive and retroductive) may be applied in critical realism, but the generation of knowledge comes mainly from abductive and retroductive reasoning (Danermark et al 2019). Abduction is a process of re-description and recontextualization where the empirical findings are described, interpreted, and explained within the frame of existing theories or concepts (Danermark et al 2019). Retroduction is a closely connected process in which the theories used in the abductive stage are used to construct the underlying causal mechanisms, and the contexts influencing them, which explain the phenomena under study (Danermark et al 2019). Extensive study designs may allow underlying mechanisms in a specific context to be identified through abduction, but as study designs become increasingly intensive they allow the possibility of retroduction and the consideration of how contexts and mechanisms interact to produce the outcome (Ackroyd and Karlsson 2014).

The second continuum of critical realist study designs relates to the involvement of the researcher in applying the knowledge they produce. At one end of the continuum is detached study designs which aim to determine or diagnose the problem, but not necessarily test the propositions of underlying mechanisms and contexts that they make. At the other end is engaged study designs where the researcher uses knowledge to actively produce change as part of the research process. For example, in action research where the researcher aims to produce change in the group under study or realist evaluation which seeks to determine why programmes, policies or practices produce the outcomes they do (Ackroyd and Karlsson 2014).

Within health and specifically published dementia research, engaged study designs using realist evaluation have been used to study football reminiscence for men with dementia (Tolson and Schofield 2012), end of life care in dementia (Kupeli et al 2016), dementia care in hospitals (Handley et al 2019) and the management of faecal incontinence in dementia (Goodman et al 2017), along with heart health programmes (Clark et al 2007). Health research using detached study designs with an explanatory focus have been used to study delays to breast cancer diagnosis (Angus et al 2006), the decision making of support workers in dementia care (Kontos et al 2010), factors associated with the presence or absence of post-partum depression (Sword et al 2012), the retention of overseas nurses (O'Brien and Ackroyd 2012) and home dialysis decision making in chronic kidney disease (Harwood and Clark, 2012).

Danermark et al (2019) state that a critical realist research design should guide "the research in the identification of the causal mechanisms generating events, and the examination of how different mechanisms cooperate and, under specific circumstances, contribute to the production of concrete events and processes" (p129). The study design employed in this thesis was determined by the nature of the research question, and the group of people studied to answer the research question. There are certain circumstances or situations in which mechanisms which are usually hidden because they are counteracted by other mechanisms, become more apparent (Danermark et al 2019). Studying these situations allows a researcher to gain a clearer understanding of causal mechanisms and in the case of this study, focusing on a group of people who have not actively sought help but have been identified through an acute hospital admission, would increase the possibility of underlying causal mechanisms being identified in the retroductive process.

The systematic review in phase one identified barriers and facilitators to help seeking for a dementia diagnosis, but these were based on studies of people who had eventually been diagnosed. Little was known about the people who do not seek help for a diagnosis. Consequently, the systematic review could inform the data that would need to be collected in phases two and three, but using these findings to direct the subsequent study phases could have led to focusing on a phenomenon that does not apply to the group under study and as such would not have enabled the underlying causal mechanisms to be identified. This led to using a detached, explanatory and largely intensive design to determine the underlying mechanisms and context which prevent help seeking for a diagnosis of dementia through a process of abduction and retroduction. Danermark et al (2019) set out five stages of explanatory research based on critical realism, of which the first four have formed the basis for the design of this study. These can be found in Table 3.2, along with how the mixed method study design described previously corresponds to each of Danermark et al's (2019) stages and its application in this study. The fifth stage involves testing the propositions made in stage four with further empirical research, which was beyond the scope of this study.

As there are no 'best fit' research methods in a critical realist study, many critical realist researchers advocate methodological pluralism as the ideal way to identify causal mechanisms and the way they manifest in society (Danermark et al 2019). A view of causality which places emphasis on how and the context in which events occur, as well as the regularity of events, means that qualitative and quantitative methods can complement each other (Maxwell and Mittapalli, 2015). Harrits (2011) describes this as using quantitative methods to identify patterns and correlations in observed events and qualitative methods to "zoom in" on the

complex causal mechanisms underlying these events. This does limit the type of study design that can be used in mixed methods though. As the findings from the quantitative and qualitative phases of a study will relate to different aspects, a design that uses qualitative findings to confirm quantitative findings or vice versa would not fit with the underlying assumptions of critical realism (Zachariadis et al 2013). However, the complementarity design used in this study is compatible with the assumptions of critical realism, as the qualitative and quantitative phases aimed to explore different facets of help seeking for a dementia diagnosis. Critical realism also places value on the meaning individuals attribute to phenomena, in addition to the physical and social contexts in which phenomena occur. This again supports the use of both qualitative and quantitative methods, although it is qualitative methods that are most often used to understand people's perspectives, beliefs, and values. As the aim in critical realism is to uncover the underlying structures and causal mechanisms, there is a tendency for critical realist mixed method studies to prioritise qualitative over quantitative methods. In this study the qualitative methods used to understand the help seeking experiences of carers predominated, but the quantitative methods made an important contribution to the overall results by identifying how people who do not seek help may differ demographically and/or clinically from those who do seek help.

Table 3.2 Stages of explanatory research using critical realism and their application to this study

Stages of Explanatory research	**Application in this study**
1: Description – descriptions of the events, situations, and activities to be studied or explained using qualitative and/or quantitative methods	• Systematic review of the literature on barriers and facilitators to help seeking for a diagnosis of dementia (Chapter Four) • Interviews with carers of people diagnosed with dementia during or following an acute hospital admission (Chapter Five) • Collection of memory clinic and hospital records data for people referred to a memory clinic by different sources (Chapter Six)

2: Analytical resolution – separating and dissolving the composite and complex by distinguishing various components, aspects, dimensions and levels of analysis	• Thematic analysis of barriers and facilitators in systematic review (Chapter Four) • Thematic analysis of interview data (Chapter Five) • Statistical analysis of memory clinic and hospital record data (Chapter Six) • Analysis of integrated findings (Chapter Seven)
3: Abduction/ theoretical redescription – various theoretical interpretive frameworks are examined to specify the phenomena and put it into the context of possible explanations	• Explanation of findings using abductive reasoning (Chapter Eight)
4: Retroduction – to find answers to questions like 'What properties must exist for X to be what X is'? for each of the structures focused on	• Identification and discussion of the causal mechanisms preventing help seeking (Chapter Eight)

3.4 Methods

The mixed methods design of this study was comprised of four phases and the following sections will describe the methods used to conduct each phase.

- Phase One: Systematic review – section 3.5 will describe the methods used to conduct the systematic review of the barriers and facilitators to help seeking for a diagnosis of dementia from the perspective of people living with dementia and their carers, and the rationale for these.
- Phase Two: Qualitative exploration – section 3.6 will describe the methods used to conduct the qualitative interviews with carers of people who had been diagnosed with dementia during or following an acute hospital admission. The recruitment challenges faced along with the steps taken to address these will be outlined, along with the rationale for the data collection and analysis methods.

- Phase Three: Quantitative exploration – section 3.7 will describe the methods used to conduct a retrospective cohort analysis of people referred to a memory clinic in inner London.
- Phase Four: Integration of findings – section 3.8 will describe the methods used to integrate the findings of phase one, two and three.

3.5 Phase One: Systematic Review

The overview of the literature related to help seeking for a diagnosis of dementia synthesised in Chapter Two identified that despite a considerable body of work aiming to determine the barriers to seeking help from the perspective of carers and people living with dementia, this work had not been systematically reviewed. As the overall aim of the study was to understand why people may not seek help for a diagnosis of dementia, having a comprehensive understanding of the research to date on the barriers and facilitators to diagnosis was important. The existing literature base was diverse and was comprised of quantitative, qualitative, and mixed methods studies. Therefore, a mixed studies review was determined to be the most appropriate way to systematically appraise the literature and this formed phase one of the study. A mixed studies review is considered appropriate for context sensitive and complex health interventions (Pluye and Hong 2014) and the published review conducted as phase one of the study can be found in Chapter Four. The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Hong et al 2018) and was registered in advance on PROSPERO (CRD42018092524). The PRISMA checklist and PROSPERO registration can be found in Appendix 1 and 2 respectively.

3.5.1 Aim and review design

The aim of the mixed studies review was to identify barriers and facilitators to help seeking for a dementia diagnosis from the perspective of carers and people living with dementia. A mixed studies review, or mixed methods research synthesis, should follow the same principles as mixed methods research by clearly stating the rationale, priority, sequencing, analysis and integration of findings (Heyvaert et al 2013). The rationale for the review was to provide a comprehensive synthesis of the literature related to the barriers and facilitators to help seeking. It was the intention that the qualitative and quantitative data would provide corroboration of the barriers and facilitators, as well bringing breadth and depth to the review.

As with mixed methods research designs there are typologies of mixed studies review designs. Pluye and Hong (2014) describe three types of mixed studies reviews – a sequential exploratory synthesis, a sequential explanatory synthesis, and a convergent synthesis. The design chosen for the review conducted as part of this study was a convergent synthesis. This type of design is best used when the qualitative and quantitative literature related to the topic can both address the same research question, findings will be able to confirm, refute or extend each other and any differences in the findings would not justify a separate analyses or synthesis (Sandelowski et al 2006). In this review equal priority was given to qualitative and quantitative data, with both types of data collected and extracted simultaneously. Hong et al (2017) differentiate between two types of convergent synthesis: a data-based convergent synthesis design and a results-based convergent synthesis design. The data-based convergent synthesis design was used in this review as the data from quantitative studies and the quantitative data from mixed methods studies were transformed into qualitative data so that all data were synthesised together. This is in comparison to a results-based convergent synthesis where the two types of data are analysed separately and then integrated. The review design based on the typology of Hong et al (2017) can be seen in diagrammatic form in Figure in 3.3 and each step of the review process is described in more detail below.

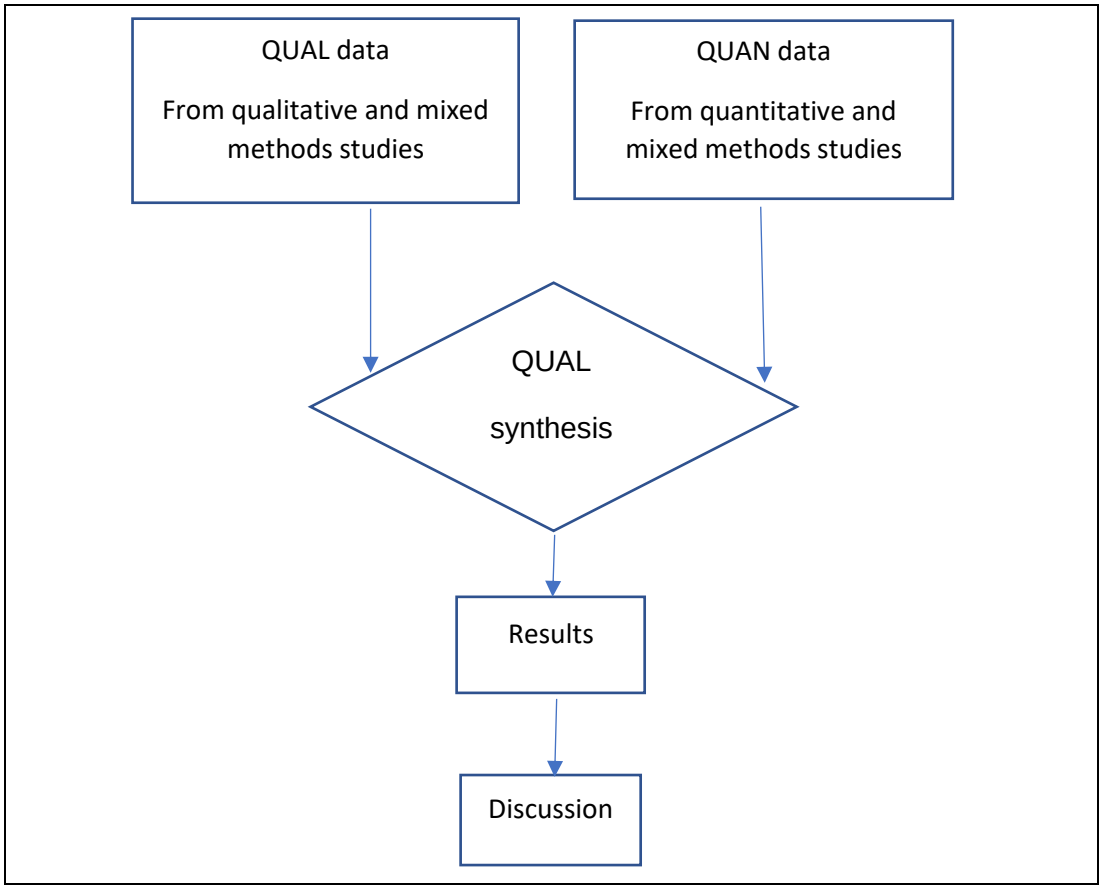


Figure 3.3 Mixed Studies Review Design

3.5.2 Eligibility criteria

Qualitative, quantitative and mixed methods primary research studies were included based on the eligibility criteria in table 3.3.

Table 3.3 Eligibility criteria

Inclusion Criteria • Studies with an aim/ research question or questions asked during data collection that related to barriers or facilitators to help seeking for a diagnosis of dementia. • Findings from the perspective of carers or people subsequently diagnosed with any sub type of dementia (self- confirmed or confirmed as part of the study) • Carers who provide informal or unpaid care
Exclusion Criteria • Reporting only demographic characteristics in relation to help seeking • Findings related to help seeking for care or support post diagnosis. • Reporting barriers or facilitators after first contact with a health professional
Limits • No date limits were imposed. • English language publications only • "adults aged 18-64 and aged 65+" in Embase only due to the large number of search results.

Criteria were based on **PIO** - **P**opulation – carers who provide unpaid or informal care and/or people diagnosed with dementia, **I**ntervention – seeking help from a health professional for a diagnosis of dementia and **O**utcome – a diagnosis of any subtype of dementia.

As was evident in the overview of literature in Chapter Two, many studies of pathways to diagnosis and beyond include barriers and facilitators in the pre-diagnosis period without specifically aiming to identify these, so studies that included questions related to barriers or facilitators, even if this was not the primary aim of the study were eligible for inclusion. Although the overview in chapter two identified that delays to diagnosis often occur after first seeking help from a health care professional, the focus of the review was on help seeking that

led to an initial interaction with a health care professional regarding dementia symptoms, so did not necessarily need to result in a diagnosis at that point. Studies reporting barriers or facilitators after first contact with a health professional were not eligible, as the objective was to determine factors influencing the initial help seeking of the person living with dementia and/or their carer. To ensure that all possible eligible studies were included, no date limits were set on the search and an age limit was set in one database only, as the initial search results were unmanageable. There was a possible risk of bias by including only English language studies, but translation of studies was beyond the scope of this unfunded study.

3.5.3 Search Strategy

Keywords for the search strategy were based on three concepts: dementia, help seeking and the timing of diagnosis. Subject headings and truncated keywords were used in the search of each concept and then concepts were combined using "AND" for the final search. The search terms used can be found in Table 3.4. The full search strategy for one database can be found in Appendix 3. Nine databases were searched (MEDLINE Complete, CINAHL Complete, PsychARTICLES, PsychINFO, SocINDEX, Embase, Cochrane Central Register of Controlled Trials, BASE, Open Grey) between March-April 2018 by the researcher. Two grey literature databases - BASE and Open Grey, were included to ensure all relevant studies were identified and to reduce publication bias. Where the search results were conference or poster abstracts, further searches to identify full publications were made and the original authors contacted for further information when necessary. The database search was supplemented by a hand search of the reference lists of the final included articles and the systematic reviews included in Chapter Two.

Table 3.4 Search Terms

Concepts	**Search terms**
Dementia	Dementia OR Frontotemporal dementia OR Vascular dementia OR Multi-infarct dementia OR Alzheimer's disease OR Lewy Body disease OR memory disorder OR memory problem OR cognitive dysfunction OR cognition disorder OR neurocognitive disorder OR confusion OR forgetfulness
Help seeking	help-seeking behaviour OR help seeking OR help-seeking OR seeking OR access OR delay OR avoid OR barrier OR obstacle OR facilitator OR enabler OR trigger

Timing of Diagnosis	Diagnosis OR delayed diagnosis OR early diagnosis OR late diagnosis OR undiagnosed OR undetected

3.5.4 Study selection and data extraction

All search results were imported into Endnote X9 (Clarivate Analytics 2013), a reference management tool and duplicates removed. They were then imported into an online systematic review management tool, Rayyan (Ouzzani et al 2016), which facilitated the blind independent review of the title and abstract of all results by the researcher and another member of the supervising team. Where there was uncertainty about the inclusion of a study, this was discussed between the researcher and a supervisor reviewing the results, with any further conflict resolved with discussion between the whole supervising team. As the researcher and three supervisors were involved in study selection, inter-rater reliability was calculated using Kappa to ensure accuracy and precision in the study selection (Belur et al 2018). The full text of all eligible articles were then reviewed independently against the eligibility criteria by the researcher and another member of the supervising team, with conflicts resolved as before.

A data extraction form was compiled to ensure standardisation of the data extracted from each article. This was piloted with the first ten eligible articles and minor changes made to ensure all relevant data were being extracted. The data extraction form can be found in Appendix 4. Both qualitative and quantitative data were recorded on the data extraction form with both types of data, if relevant to the research question, extracted from mixed methods studies. Frantzen and Fetters (2016) state that when including mixed methods studies in a review it is important to make a distinction between *data* and *evidence*, with data being unbiased published results and evidence being the integration of qualitative and quantitative data within the study. For this review only *data* from mixed methods studies were extracted due to the type of mixed methods studies included and the lack of integration of results in these studies. However, *evidence* in the form of study authors interpretations of their findings were also extracted for all studies.

The researcher extracted data from all eligible articles and 25% of these were checked by a member of the supervising team for accuracy. Where multiple articles reported the same study, data were extracted onto the same form to ensure no omissions and to identify inconsistencies. Study authors were contacted for additional information where necessary.

3.5.5 Critical appraisal

The quality or critical appraisal conducted for a review is a "systematic and careful examination of studies to ensure they are trustworthy, valid and reliable" and usually involves the use of a checklist to ensure consistency and transparency (Hong et al 2019). Such tools are often designed for specific methods and as such multiple tools would be needed for a mixed studies review, leading to results that are difficult to compare. Consequently, the identification of an uncomplicated tool that is capable of assessing all study types, including mixed methods studies is deemed essential (Frantzen and Fetters, 2016). The Mixed Methods Appraisal Tool (MMAT) was designed for use specifically in mixed studies reviews and was most recently reviewed and updated in 2018 to improve content validity (Hong et al 2019). This was the tool of choice for critical appraisal of the studies in this systematic review. MMAT consists of two screening questions and then a set of five questions related to the type of study - qualitative, quantitative randomised controlled trials, quantitative nonrandomized and quantitative descriptive. This is followed by five additional questions for mixed methods studies. A copy of the MMAT tool used in this study can be found in Appendix 5. All the included studies were independently assessed by the researcher and one other member of the supervising team and any uncertainty or disagreements were resolved by discussion. Although some critical appraisal tools have a numerical scoring system so that studies can be ranked in terms of their quality, in the most recent version of the MMAT tool the authors have removed their scoring system. Their rationale for this was based on an overall score not providing enough detail as to the elements of the study that are judged to be of less quality (Hong et al 2019). No studies were excluded from this review based on the critical appraisal to ensure that all potentially valuable studies were included in the final synthesis. An overview of the critical appraisal was included in the review to alert the reader to any potential risk of bias. This can be found with the systematic review in Chapter Four.

3.5.6 Data Synthesis

A data-based convergent qualitative synthesis approach was used in this review. Where quantitative, qualitative, and mixed method studies are included and all data are transformed to qualitative data, this can also be called an advanced convergent qualitative meta-integration (Frantzen and Fetters 2016). There are a number of options for transforming quantitative data into qualitative data and in this study a thematic analysis approach was used. This involved a categorising and pooling of data based on similarities (Lizarondo et al 2020). This approach

suited the type of data that was extracted as it was possible to create themes which related to specific types of barriers and facilitators and the quantitative data tended to be survey data where respondents would rate their agreement against a pre-defined list of barriers or facilitators. Consequently, quantitative data were transformed to qualitative data in the following way - where a proportion of respondents in a study agreed with a specific barrier such as lack of knowledge, this was represented qualitatively as a 'lack of knowledge'. Following transformation of the data, Frantzen and Fetters (2016) advocate a mindful comparison of the qualitative and transformed quantitative data. This involves "a conscious and intentional consideration of the findings" (p2265), specifically the similarities and differences between the qualitative data and transformed quantitative data. As the quantitative data extracted for this review were a suitable fit for barrier and facilitator themes, there was less complexity in the transformation than there may be with other types of data. However, there were several issues to consider. Data from the quantitative studies were largely from surveys where respondents were given a set number of barriers or facilitators to rate their agreement with, limiting respondents' answers and potentially omitting other important barriers or facilitators. However, some studies reported that their survey items were generated following focus groups with carers or a review of the literature and a comparison between the qualitative and transformed quantitative data revealed good agreement between data within themes. The other consideration was whether to include all barriers or facilitators listed in quantitative surveys, regardless of the proportion of people agreeing with them. As the decision had been to give equal priority to qualitative and quantitative data in the review, all barriers and facilitators reported by respondents in quantitative studies were coded and included, to ensure parity between barriers and facilitators reported in larger quantitative samples and those reported in the smaller samples of qualitative studies. However, in doing so it is acknowledged that this had the potential to overestimate the strength of some barriers or facilitators and could be considered a limitation of the review.

3.6 Phase Two: Qualitative exploration methods

As the dominant phase of this mixed methods study, the aim of the qualitative phase was to explore the experience of carers of people diagnosed with dementia during or following a hospital admission, to understand why they had not sought help beforehand. From a critical realist perspective, it was intended that by understanding the experiences of carers in the

empirical domain we may gain insight into the causal mechanisms of the real domain that prevented them from seeking help.

The original intention for the qualitative phase had been to interview people living with dementia and their carers, following their diagnosis in hospital. Due to recruitment difficulties this had to be adapted. This section describes the research design for this study phase, the rationale for decisions taken and the challenges encountered, ensuring the Consolidated Criteria for Reporting Qualitative Research (COREQ) are followed (Tong et al 2007). The COREQ checklist is included in Appendix 6.

3.6.1 Participant selection

Gaining access to a population who are not actively seeking help is a challenge. The introduction of case finding initiatives in acute care settings, which aimed to identify people with symptoms of dementia if they were admitted to hospital and refer them for assessment, created an opportunity to access people who had not sought help previously in primary care. Although nationally the referral process varied between hospital trusts, the trust which the researcher had previously been employed at chose to refer people with suspected dementia to the psychiatric liaison teams within the hospital. This meant these teams had access to people who were being diagnosed with dementia, having not actively sought help previously. The study initially aimed to use this hospital trust and the patients they were seeing as the setting and participants.

3.6.1.1 Sampling

Selecting settings and participants for qualitative research aims to identify individuals who exhibit the phenomena you are interested in, who are accessible and most likely to be able to help you gain the understanding you seek (Maxwell, 2012). This process is usually referred to as purposive or purposeful sampling, although selecting settings and participants that are accessible and most likely to be conducive to research can also be considered convenience sampling (Maxwell 2012, Cresswell 2013). Sampling strategies can impact the validity of the findings but the practicalities of identifying research settings and participants needs to be considered and flexibility with the use of more than one sampling method may be necessary in some circumstances (Maxwell 2012, Cresswell 2013). The sampling strategy used in this study was purposive sampling and participants were intended to be people diagnosed during or following an acute hospital admission and their carers, as they had not sought help previously

in primary care. As such their experiences would contribute towards an understanding of why people may not seek help for a dementia diagnosis.

The psychiatric liaison teams of three acute hospitals within a large NHS trust, which the researcher was previously employed at, were chosen as the settings from which participants would be recruited. They would act as Participant Identification Centres, involved in identifying eligible participants and giving out study information, but not involved in consent or data collection. The researcher had personal contacts with nurses and doctors in each of the three liaison teams. It was estimated by the teams that in total they made approximately ten new dementia diagnoses each month.

The three hospitals were geographically close, but each was situated in a different London borough. All three boroughs have populations who are ethnically diverse with between 48-72% of residents in the boroughs from a minority ethnic background. The three boroughs all have an average age below the national average, ranging from 31 years – 34 years (Tower Hamlets Council 2018, London Borough of Waltham Forest 2020, ESRIUK 2020).

3.6.1.2 Eligibility

People diagnosed with dementia during their hospital admission and their carers were the intended participants. To be eligible, participants needed to have received a diagnosis of dementia during their hospital admission or be the carer or next of kin of the person diagnosed. The diagnosis included any sub-type of dementia and any level of severity. Participants needed to have been informed of the diagnosis and speak English sufficiently to be able to participate in an interview. Unfortunately, no people living with dementia were recruited for the study and this will be discussed in more detail in section 3.6.3.

3.6.1.3 Sample size

In this study an estimated sample size was required for ethical approval and the figure of 5-6 people living with dementia and 5-6 carer participants was given, with the plan to increase the number of carer participants if recruiting people living with dementia was difficult. These estimated figures were determined by looking at the reports of other qualitative studies that included people living with dementia and carers. Sim et al (2018) caution against this strategy as it assumes a level of homogeneity amongst the studies, even if they have the same philosophical approach.

Attempts to devise methods for determining sample size in qualitative studies have been a topic of considerable debate in qualitative research methods literature in the last few years (Blaikie, 2018). Methods to determine sample size (such as those by Francis et al 2010, Guest et al 2006 and Fugard and Potts 2015) often focus on when data saturation in qualitative analysis is reached. But these models make assumptions about what constitutes a theme, how themes are derived and the number of instances of a theme required, all of which can vary greatly depending on the approach employed by the researcher and the study's aim (Emmel 2015, Sim et al 2018).

It is acknowledged that the approach used in this study was far from ideal, especially as the studies reviewed to determine this estimate were not critical realist studies. However, as the study progressed, a more iterative process was used to determine the number of participants required and when data saturation was considered to have been met. This will be discussed in section 3.6.5.1.

3.6.2 Recruitment procedure

Participants for this study were identified by three psychiatric liaison teams. As the gatekeepers to the participants, establishing a relationship with staff in the teams was essential. Gatekeepers are described as intermediaries in the research process, with the power to grant or withhold access to participants (Crowhurst and Kennedy-Macfoy 2013, Clark 2010). Research involving people living with dementia can have multiple gatekeepers including ethics committees, managers, practitioners, and carers (Hellstrom et al 2007). Their roles are often seen in a purely mechanistic way in terms of their ability to grant access to participants, but gatekeepers can have a significant influence on research relationships and a reflexive approach is required to consider the dynamics of the gatekeeper – researcher relationship and the impact this may have on a study (Crowhurst and Kennedy-Macfoy 2013). The positioning of the researcher in this study and how their thoughts and experience may have influenced the study design and interpretation of the results is considered in Chapter Seven.

The researcher began by meeting with the manager of the nursing and therapy staff within the three teams, as these staff members approached potential participants about the study. Permission of the team manager to use the teams as participant identification sites was also required for NHS Research and Development (R&D) capacity and capability approval. The team manager had previous experience of being involved in research and was very keen for her staff to be involved. This may be perceived as an advantage, but Dempsey et al (2016) caution that

lower level gatekeepers may be less keen to help if they feel they are being made to participate. The study was presented to nursing and therapy staff of all three teams at one of their team meetings, information was provided about the background and aims of the study and what would be required of them. This was also an opportunity to gather their thoughts on the participant identification process and what would work best for them. An information sheet was produced outlining the process and possible concerns and this was used to facilitate discussion in the meetings. A copy of this can be found in Appendix 7. None of the staff had previous experience or involvement in research and although they had some concerns about approaching people living with dementia about research, they were also keen to help. Meetings with the consultant geriatrician or psychiatrist in each team also took place, as they had an important role in ensuring the nursing and therapy staff were aware of any new diagnoses. Their support of the study would also influence whether their teams felt able to approach potential participants or to discuss the suitability of participants in team meetings.

Four participant information sheets about the study were produced, two carer versions, one long version for people living with dementia and one short easy read version for people living with dementia. These can be found in Appendix 8-11. The participant information sheet, along with a cover letter, was given to the person living with dementia and/or their carer shortly after diagnosis when they were being seen in hospital by a member of the psychiatric liaison team for post diagnostic support. The participant information sheet and cover letter contained the researcher's contact details but also stated that if interested the person could let the liaison team member know and they would pass on their contact details to the researcher. Each team were visited in the weeks after the team meeting to give them participant information sheets and cover letters and to address any concerns or queries they had about their role in identifying participants. For data protection reasons it was agreed that team members would send the researcher an email or telephone message to say they had identified an interested participant. The researcher then contacted the team member to obtain the participant's details. Following this, the potential participant was contacted by the researcher to discuss the study further and arrange a time for the interview.

3.6.3 Recruitment difficulties

There were considerable recruitment difficulties in the first twelve months. Only one team was able to identify participants who were happy to have their contact details forwarded to the researcher. Five carers of people diagnosed with dementia were recruited, with four of these

carers consenting to be interviewed in the first twelve months. No people living with dementia were identified as potential participants by the teams.

One team (Team A) were more successful in identifying potential participants than the other two. There was a slightly larger proportion of older people in the local population served by the hospital in which Team A worked, consequently it is possible that more eligible patients were admitted to the hospital. Also due to concurrent activities, the researcher visited the hospital in which Team A were based every few weeks, so frequent informal and in-person contact was easier to maintain.

Despite this, the number of participants identified was small. Assisting with a research study can add an extra burden to an already busy workload, meaning gatekeepers are reluctant to assist or they may simply forget (Dempsey et al 2016). Lowery et al (2011), following poor recruitment of people living with dementia by NHS staff to a clinical trial, explored staff reluctance to recruit to low risk studies. Staff expressed feelings of accountability for the study's value and conduct, and with no control over this, felt a responsibility if participants did not benefit from the study or came to harm. They also feared overburdening vulnerable participants and felt recruitment was a low priority in their clinical work.

Discussions with the teams at the start of this study, aimed to address any concerns about people living with dementia participating in research, but no major concerns had been expressed. Other studies have also recognised that gatekeepers can be overprotective and may deny people living with the dementia opportunities to take part in research if they feel that the person living with dementia may come to harm (Waite et al 2019, McKeown et al 2010). It is possible that both staff in the liaison teams and the carers they approached had similar concerns and on reflection it would have been helpful for the researcher to have explored these issues specifically with the teams over the course of the recruitment period. As potential participants with dementia were in hospital with a physical health problem, and possible co-morbidities, it is likely that staff and carers thought they were too unwell to take part. Of the five carers who had initially expressed a desire to take part, four of the people with dementia they cared for were discharged from hospital to a care home for the first time and one person with dementia died during their admission.

Concerns about confidence in discussing research and feeling overprotective may also have extended to the identification of potential carer participants. In addition, carers may have felt unable to decide about participating in research whilst the person they cared for was in hospital. They were often negotiating difficult discharge decisions or coping with the

deteriorating health of the person with dementia. Kowlanowski et al (2013) found that carers were often facing mental and physical frailties of the person living with dementia during an acute admission and as such first contacts related to research needed to be sensitive and attentive to these issues. Adjusting to the diagnosis of dementia was a common reason for people not wishing to take part in an intervention study that aimed to recruit people living with dementia and their carers via memory services (Field et al, 2019). An intervention study aimed at supporting carers also found that eligible participants were often juggling the care of the person with dementia, work and family commitments and as such participating in research felt like an additional burden to them (Gelman 2010).

3.6.3.1 Steps to address recruitment difficulties

As recruitment for the study needed to improve in a timely manner, a decision to focus on recruiting carer participants only, for the remainder of the study was made. This limited the ability of the study to explore what deters people living with dementia from seeking help for their symptoms. However, carers are often the people who initiate and/or support help seeking and therefore hearing their experiences would still meet the aims of this study.

Two additional recruitment strategies were put in place. Approval from the Health Research Authority and local Research and Development department were sought to include the psychiatric liaison team of another hospital trust in London as an additional participant identification centre. Contacts with a psychiatrist within this team were already established, and the team were very experienced in recruiting for and carrying out research with people living with dementia. Similar referral processes had been used in this trust, whereby people identified as having possible dementia were referred to the liaison team within the hospital. The team estimated that they could make between 8-10 new dementia diagnoses each month. They were keen to help and meetings were arranged to explain the aim of the study and participant identification procedures.

The second strategy was to register the study on Join Dementia Research (JDR). Join Dementia Research is a website run by the National Institute for Health Research (NIHR) and is a service that allows people to register their interest in participating in dementia research and be matched to suitable studies. Further ethical approval was not required for this. The Health Research Authority were informed of the change via a non-substantial amendment and a data sharing agreement was set up between the university and the Department for Health and Social Care for access to the data. Carers who had signed up to JDR were different from those

carers who were being approached by the hospital teams, in that the diagnosis of the person they cared for may have been made a few years previously. The study was advertised to carers across the whole of the greater London area, so it was likely that the referral and diagnostic procedure in the hospitals they had attended differed from the two participant identification centres already in place. For this reason, the eligibility criteria were amended to include people who had been diagnosed during *or following* a hospital admission. The initial identification of symptoms had to have been made during a hospital admission, but the diagnosis could have been made subsequently in the community, as this was the procedure followed by some London trusts. Within a four-month period, eight eligible carers from the greater London area had consented to be interviewed, bringing the total number of carer participants to twelve. Whilst this proved to be the most successful recruitment strategy for the study, Bartlett et al (2019) provide a note of caution when using internet research registries such as JDR. When recruiting people living with dementia, such registries are likely to be used by younger people and those with less severe impairment. Although JDR was used to recruit carers only, it is possible that younger carers and those more familiar with using the internet and email were more likely to have registered on the site, possibly reducing the representativeness of the sample.

No carers expressed an interest in the study from the second hospital trust. This was disappointing as the liaison team were very research focused and experienced. However, it is recognised that the number of other studies running at a site may affect the engagement of staff (Field et al 2019). It also suggests that recruiting carers at the time of diagnosis in hospital is a particularly challenging recruitment strategy.

It was difficult to determine exact non-participation rates for the study as the researcher had not asked the psychiatric liaison teams to keep a record of how many new diagnoses were made each month and how many cover letters and information sheets they gave out to people diagnosed with dementia and carers. With hindsight this would have been helpful to determine if the recruitment problems were related to the potential numbers of participants, the gatekeepers or potential participants not wishing to take part.

3.6.4 Data Collection

In- depth interviews were considered the most appropriate data collection method for exploring carer's individual experiences and feelings about the diagnosis of the person they cared for in this study. In depth interviews are often used to explore people's experiences of

personal or sensitive topics and seek “deep information and understanding” about an experience that can only be known by the participant (Braun and Clarke 2013, Johnson and Rowlands et al 2014:102). Carers can be considered a vulnerable group for multiple reasons. Caregiving roles have been found to negatively impact physical and mental health, social and financial wellbeing and employment and discussion about caregiving experiences may involve strong emotions related to family relationships, caregiving burden, guilt and stress (Larkin et al 2018, Funk and Stajduhar, 2009). Focus groups may have precluded carers from talking in detail about their own experiences and feelings, as they are generally used to obtain the views and perspectives of a group of people on a specific topic (Braun and Clarke 2013). They would also have been challenging from a practical point of view due to the small number of carers recruited over a long period of time.

3.6.4.1 Interview topic guide

The interviews were semi-structured, with a topic guide devised to include a minimal number of open questions and numerous prompts. The questions revolved around three time periods – pre-diagnosis, diagnosis, and post diagnosis (Appendix 12). Maxwell (2012) stresses that interview questions should not necessarily be a reformulation of the research question but questions most likely to gain the understanding required. The aim was to encourage carers to talk as freely as possible about their experiences, thoughts and feelings surrounding the dementia diagnosis, with prompts, as necessary.

Piloting an interview guide is often recommended, but as potential participants in this study were considered vulnerable, it would not have been appropriate to pilot the questions and then not use the data collected. The topic guide was developed following a review of qualitative research methods literature and published qualitative studies but was also reviewed by people living with dementia and their carers as part of the ethical approval process (see section 3.10.1). When formal piloting is not possible it is recommended to review the questions after the first few interviews (Braun and Clarke 2013). In this study the interview guide was reviewed by the researcher and supervising team after the first four interviews to determine whether the required type and depth of information was being collected. It was felt that no changes to the interview guide were required.

3.6.4.2 Conducting the interviews

Participants were interviewed once in a setting and at a time of their choice. The original study protocol had included a second interview three- six months after the first interview, to further explore carer feelings about diagnosis. However, due to the lengthy recruitment process, one interview was determined to be sufficient to answer the research question. Allowing a participant to choose the time and venue for an interview gives them a sense of control and allows them to choose a place they feel safe and comfortable in (Elmir et al 2011). Seven carers chose to be interviewed at their home, two at their workplace, one in a local coffee shop, one at a public venue connected to their work and one at the hospital. As all interviews took place off the university campus, the researcher ensured that guidance on lone working was followed and that a designated person at the university was aware of the time and venue of all interviews.

Developing a rapport and minimising power imbalances between researcher and interview participants is essential and even more so when discussing sensitive topics (Elmir et al 2011). Although the realities of doing so are more complex and the term "rapport" in relation to research interviews has been seen to be problematic, as it relates to a "single continuous variable, rather than emphasizing the nature of the relationship" (Maxwell, 2012:101). It can also be argued that power imbalances will always exist as the researcher has the power to structure the interview. Knapik (2006) describes how the researcher needs to take the role of learner in the interview and ensure participants feel like they are the experts of their experiences.

Contacting some carers by phone to arrange the interview was an opportunity to begin establishing a relationship with participants, although some arrangements were made via email. All interviews were audiotaped, and the researcher used the opportunity of setting up the audio recorder to engage in small talk and develop rapport. Written informed consent was gained from all participants prior to the interview commencing (Appendix 13), and this allowed more opportunities to talk before the interview began.

During introductions, the researcher shared information about their background and that their clinical work had often been focused on supporting carers like themselves during the diagnostic process. Dempsey et al (2016) discuss how a role conflict can arise when the carer knows that a researcher has a healthcare background, as they may ask questions about what they would do in a particular situation or ask for health-related advice. This did happen during

some of interviews in this study, particularly when carers were describing symptoms they had witnessed or behaviours exhibited by the person living with dementia, that they could not explain. This did not help with the researcher's intention to situate themselves in the role of learner, as in asking questions, the carer's positioned the researcher in the role of the expert. It was important to try to move away from the topic of discussion without the carer feeling dismissed. The researcher tried to give minimal information to answer their question and focused on reassuring the carer that the symptom was common or that they had done a good job in caring for the person, whilst trying to steer the conversation back to the interview topic.

It is recommended that researchers use their topic guide as little as possible during an interview so that they maintain the role of active listener (Dempsey et al 2016). The researcher chose not to make any notes during the interview to facilitate this, making notes after leaving the interview setting. The first question invited carers to talk about when they first noticed there was something wrong with their relative's memory. Starting at this point most carers continued, without the need for prompts, to talk more about their relative's diagnosis journey. This enabled the researcher to probe deeper into aspects of the journey they had already described without always needing to follow the topic guide and ensured that the interviews flowed in a conversation style. This was easier in some interviews than others as some carers talked freely and expressively about their experiences, others gave shorter answers and required more probing for details. Warren (2014) gives four reasons why some interview participants are less expressive than others including being less verbal, being less interested in the topic, being fearful of discussing the topic or using their silence to express their challenging feelings about the topic. As carers in this study had volunteered to participate, it is likely they were interested in the topic. But some carers had less awareness of the person living with dementia's problems in the pre-diagnostic phase and it seemed clear that they had not been inclined or had the opportunity to reflect on their situation before the interview. This became clear as some participants who appeared to have little to say in answer to earlier questions talked more about how they felt as the interview progressed.

Knapik (2006) in her study of the experience of participating in research interviews found that participants interpreted the body language and facial expressions of the interviewer and adjusted their responses accordingly. Hence it was important to find a balance throughout the interview between being engaged, expressing appropriate empathic responses and reinforcers, and trying not to express surprise or shock that might deter the carer from continuing with their line of conversation.

All the interviews came to a natural conclusion and opportunity was provided for carers to add anything else they felt was important. Carers used this as an opportunity to talk about things not directly related to the topic but that they thought people needed to know. Spending time towards the end of the interview talking about less emotional or intense topics, acknowledging the contribution the participant has made and engaging in social conversation is found to help the participant adjust from a research context back to their everyday life (Corbin & Morse 2003, Dempsey et al 2016). Carers were also given the opportunity to receive a copy of their transcript and a summary of the findings when the study was finished.

3.6.5 Data Analysis

Each interview was transcribed verbatim. Five of the interviews were transcribed by the researcher and the remining seven by a transcription agency who have a contract with the School of Health Sciences at the university. This allowed the researcher to understand the transcription process and become immersed in the data but was balanced with practicality and the need for transcription to be completed in a timely manner.

Interview transcripts were analysed using an inductive, latent thematic analysis approach (Braun and Clarke, 2006). Thematic analysis is a term often used to describe the analytic process in qualitative research, but historically was not well defined or explained. Braun and Clarke's (2006) guide to conducting thematic analysis aimed to address this but the term continues to be used in analyses that are inconsistent with their original paper and subsequent writings have sought to further clarify its appropriate use (Terry et al 2017, Clarke and Braun 2018). It is the flexibility and theoretical independence of thematic analysis that makes it attractive to qualitative researchers but can also result in its misinterpretation (Terry et al, 2017). Consequently, it is important to explicitly state choices made in doing thematic analysis.

The analysis in this study was inductive, as themes were identified from the data without any prior coding or theoretical framework guiding the analysis (Braun and Clarke, 2006). This was deemed appropriate as this group of carers have not been well studied and the aim was to understand their experiences as fully as possible. It is important to acknowledge that the researcher brings their own subjectivity to the analysis, so themes can never be purely data driven (Terry et al, 2017). Indeed, in critical realism, even when a detached stance in study design is taken, the researcher can never be truly detached. As social structures are

constructed and reconstructed by agents over the course of time, the critical realist researcher will to some extent play a part in this (Ackroyd and Karlsson 2014).

The analysis can also be described as 'latent' as it aims to "identify or examine the underlying ideas, assumptions and conceptualisations" rather than simply report patterns in what is being said (Braun and Clark, 2006:13). This level of analysis is appropriate for a critical realist study as it is a "method which works both to reflect reality, and to unpick or unravel the surface of 'reality'." (Braun and Clark, 2006:9), which is essential to identify underlying causal mechanisms.

Maxwell and Miller (2012) make a distinction between categorising and connecting strategies in qualitative data analysis. A critique of coding processes in qualitative data analysis is that they are often only concerned with comparing data to find similarities or differences and in doing so neglect the context in which the data is situated (Maxwell and Miller, 2012). Context is important in critical realist studies, as it is the interaction between mechanisms and particular circumstances that produce events. So, data analysis needs to consider the connections between events and thoughts or contiguity relationships as well as similarity relationships (Maxwell and Miller 2012).

Narrative and contextual analysis approaches are considered to be strategies that primarily focus on contiguity relationships within data, although these can be critiqued for potentially missing important insights that come from making comparisons within the data (Maxwell and Miller, 2012). Consequently, an analytic strategy that combines both contiguity and similarity is preferred in critical realism.

The thematic analysis employed in this study aimed to consider both similarity and contiguity relationships in the data. Although the coding process involved comparing and contrasting transcripts to establish themes, care was taken to present themes in a sequence of events from first symptoms to post diagnosis and to be mindful of the mental processes of carers throughout the diagnostic journey, as well as the physical sequence of events.

Braun and Clark (2006) describe a six-step process for conducting thematic analysis. The six steps along with how each step was conducted in this study can be found in table 3.5.

Table 3.5 Steps of Thematic Analysis process in this study

Steps of Thematic analysis process (Braun and Clark 2006)	Thematic analysis in this study
Step 1 – Familiarising yourself with the data	Transcribing 5 interviews. Outsourcing the transcription of 7 interviews. Listened to each audio recording whilst reading each transcript twice, making corrections to transcripts as necessary and making notes of initial thoughts.
Step 2 – Generating initial codes	Coding of each transcript using NVivo by the researcher (QSR International Pty Ltd, 2018). Codes were arranged into three organisational categories: pre-diagnosis, diagnosis, and post-diagnosis. Extracts of data coded inclusively with surrounding text to ensure the context was not lost. Additional field notes were made for each carer's journey from first symptoms to post diagnosis to ensure contiguity relationships identified. One member of the supervision team reviewed the coding for 25% of the transcripts.
Step 3 – Searching for themes	Mapping of codes related to each organisational category to produce first set of themes with working titles and quotes from data to support each.
Step 4 – Reviewing themes	Discussion and reflection on initial themes with supervision team. Review of data extracts within themes and refining of themes to produce thematic map.
Step 5 – defining and naming themes	Detailed analysis of each theme written to identify the underlying ideas, assumptions and conceptualisations of carers.

	Working titles of themes revised to final theme titles
Step 6 – producing the report	Writing up of each theme ensuring appropriate quotes used to both illustrate the theme and analyse the data. Ensuring the overall write up tells the 'story' of the carers' journeys and that each theme has been subjected to an interpretive analysis.

3.6.5.1 Data Saturation

As stated earlier when discussing recruitment, determining a priori sample sizes in qualitative research is not recommended. In thematic analysis consideration about sample size should relate to the ability to find patterns across the data (Terry et al 2017). Larger sample sizes may result in a lack of consideration for the complexity of the data when a 'clear conceptualisation' of what themes represent and how and why they are significant should be the aim (Braun and Clarke 2006:742). However, decisions need to be made about the point at which data collection stops, usually considered to be the point at which data saturation is reached.

Four types of saturation have been proposed – theoretical saturation, inductive thematic saturation, a priori thematic saturation, and data saturation (Saunders et al 2018). Data saturation was the definition used in this study and is considered to be "identifying redundancy in the data" and "relates to the degree to which new data repeat what was expressed in previous data" (Saunders et al 2018:1896,1897). Saturation is identified before formal data analysis takes place and when the researcher feels they are no longer hearing new information (Saunders et al 2018). The analysis in this study was not based on a pre-determined framework of categories and formal analysis had not been planned to take place until after all the interviews were completed. As such a priori saturation (when no new data can be found to support pre-determined theoretical categories), theoretical saturation (sampling until no new data can be found to support emerging themes) and inductive thematic saturation (the point at which no new codes or themes are identified) would not have been appropriate for this study.

A decision was made to continue to recruit and interview potential participants for as long as was practical, without setting a minimum or maximum number of participants needed. It was

hoped that a point would be reached where new information was no longer being heard, recruitment could stop, and formal data analysis begin. By the ninth interview the researcher was reasonably confident that no new information was being heard from participants, however, a further three carers had expressed an interest in participating within a short space of time and it seemed appropriate to the researcher to carry out these interviews as a way of testing their own sense of data saturation. The final three interviews contributed rich information to the data set but confirmed that no new information was being obtained and the point of data saturation had been reached. It is not uncommon for sampling to continue after saturation has been reached and may reflect the uncertainty with which the concept of saturation is applied within studies (Saunders et al, 2018).

3.7 Phase Three: Quantitative exploration methods

The aim of the quantitative phase of this study was to examine the characteristics of people referred to a memory clinic by their GP and via the acute hospital. A secondary aim was to determine factors associated with receiving a dementia diagnosis and survival following a diagnosis. This phase aimed to address the research questions in the Figure 3.4 and is reported following the STROBE criteria (Vandenbroucke et al 2007) in appendix 14.

- What are the characteristics (e.g. age, gender, and ethnicity) of people referred to the memory clinic via different referral sources?
- How many people referred to the clinic receive a diagnosis of dementia and does this differ between referral sources?
    - What sub-type and severity of dementia are people diagnosed with and does this differ between referral sources?
- Do the number of hospital admissions in the 12 months prior to referral differ between referral sources?
- What proportion of people are still alive six months and 12 months post referral and does this differ between referral sources?
- What are the factors associated with a diagnosis of dementia?
- What are the factors associated with death from any cause?

Figure 3.4 Research questions

A retrospective cohort analysis of anonymised secondary health care data was carried out to address these questions. The secondary health care data comprised of a database from a memory clinic in one London borough, supplemented with data from the corresponding electronic patient records. As described in the introductory chapter, help seeking for a dementia diagnosis is usually initiated in primary care, when a person who is worried about their memory or their carer seeks help from their GP. Alternatively, cognitive problems may be identified when a person is admitted to hospital for an unrelated physical problem and initiatives such as the dementia CQUIN in acute care have sought to ensure this is part of routine assessment in hospital. It was considered that people referred by their GP were more likely to have sought help for their memory problems themselves or with the support of a carer. People identified by the acute hospital and referred to the memory clinic were considered to be people who had not sought help previously in primary care.

3.7.1 Setting

The data used in the quantitative phase of this study came from the database of a memory clinic based at Newham University Hospital between 2013 and 2016. Newham is an inner London borough with an estimated population of 307,984. It has one of the most diverse populations in the UK with the lowest proportion of White British people in England and Wales, the second largest Bangladeshi population and the fourth largest Black African population (Aston-Mansfield, 2017). The population in Newham is younger than the national average with only 6.8% of the population aged 65 and over in 2015. There is a higher proportion of White British people over the age of 65 compared to other ethnic groups in the borough (Newham CCG, 2016). Newham had the highest cardiovascular premature mortality rate in London in 2013 – 2015 and a Standardised Mortality Ratio that was higher than the London and national averages (Aston-Mansfield, 2017). It also has one of the highest levels of diabetes in the country, along with high levels of cardiovascular disease and stroke (Newham CCG, 2015). In 2014 there were 998 people with a diagnosis of dementia on the Quality and Outcome Framework (QOF) register in Newham with an estimated prevalence of 1541 people with dementia in the borough (Newham CCG, 2015).

There are three reasons why this setting was chosen for this study. The researcher was previously employed by this NHS trust and had worked in the acute hospital arm of the memory clinic. Therefore, the researcher knew that a specific memory clinic database existed, that it was well maintained by the memory clinic consultant and that permission would be granted to use the database in this study.

The memory clinic itself was unique, in that it was run jointly between the acute hospital trust and local community and mental health trust. It received referrals for all people requiring a dementia assessment within the London Borough of Newham. Referrals were accepted from local GPs, the acute hospital and other community based physical and mental health teams and provided a high level of multidisciplinary assessment. Memory clinics tend to be community based and although in most places acute hospitals might make referrals to a community memory clinic, some diagnoses will be made in hospital by geriatricians, psychiatrists, and physicians. The uniqueness of the Newham memory clinic is that due to its base in the acute hospital, all diagnoses were made in conjunction with the memory clinic. As such the database included everyone referred to the memory clinic by their GP (or other community team) and everyone referred by the acute hospital. This allowed a comparison of people referred from different sources. One of the advantages of using databases in health research is that it allows an opportunity to study 'real life' experiences and detect phenomena or differences in a population that would not be possible or ethical to study in a controlled experiment (Lowrance, 2003).

The final reason related to the implementation of the acute hospital CQUIN. As this required all people over the age of 75, staying in hospital for 72 hours or more following an emergency admission, to undergo a cognitive screening test with onwards referral as necessary, hospitals were required to set up systems to ensure this was possible. This meant largely relying on junior doctors to carry out the assessment. In this hospital the presence of a well-established psychiatric liaison team for older people, who worked closely with junior doctors, meant that implementation of the CQUIN was good and appropriate referrals to the memory clinic were made for people identified as having a problem on cognitive screening. This instilled a level of confidence that people admitted to the hospital with a possible dementia were not being missed and would be included in the database.

3.7.2 Sample

The sampling technique employed in this phase of the study was determined by the database and was therefore inclusive. To ensure the data represented both people who had been referred by their GP and those referred by the acute hospital, the database needed to include details of all referrals from both sources. This corresponded with a particular time, January 2013 – June 2016. The start of this period coincided with the introduction of the acute hospital Dementia CQUIN, and prior to this it could not be determined that all possible patients had been identified. From June 2016 onwards GP referrals to the memory clinic were managed

separately within a primary care setting, so data did not exist within the database to allow comparison of patient characteristics between referral sources after this date. The total number of referrals to the clinic in this period was 2637. As not all of these referrals met the eligibility criteria for inclusion in the final analysis, it was decided to include all eligible referrals rather than a subset of the cohort. To be eligible for inclusion referrals were the first accepted referral for the patient to the clinic. Multiple referrals for the same patient and referrals for re-assessment were excluded. Referrals were also excluded for anyone with an existing diagnosis of dementia. There are different ways to calculate an adequate sample size for quantitative studies, but for regression analysis it is considered that there needs to be at least 10 outcomes for each independent variable, so given the number of eligible participants on the database and number of independent variables to be included, the sample was considered to provide sufficient power (Katz, 2011).

3.7.3 Data Collection

Data were collected from three sources – the memory clinic database, corresponding electronic patient records and the NHS Spine Demographic Batch Service (DBS). Table 3.6 details which data were extracted from each source.

Table 3.6 Data extracted by source

Data from clinic database	**Data from electronic patient record**	**Data from DBS**
Age in years	Gender	Month/ Year of death (if appropriate)
Diagnosis	Ethnicity	
Severity of dementia at time of diagnosis	No of admissions in 12 months pre referral	
Referral source	No of admissions 12 months post referral	
Plan – includes reason for not being assessed/ diagnosed	Admission diagnosis for admissions in 12 months pre and post referral	
	Past medical history problems/ diagnoses	

DBS: Demographic Batch Service

As only the anonymised data were needed, data extraction, linking between the databases and de-identification were undertaken by the Business Intelligence Unit in the trust.

3.7.4 Data cleaning and coding

Before data analysis began raw data were cleaned by removing multiple referrals for the same patient (this was possible because each patient in the dataset had been given a unique identifier) along with referrals that had been declined by the memory clinic or where the patient had an existing diagnosis of dementia. Data were coded to assign numerical codes and the details of these can be found in Appendix 15. The hospital data recorded ethnicity using eight different ethnic groups, this was recoded according to the six categories recommended by the Office for National Statistics for use in England (Office for National Statistics, 2016). Admission data related to admissions of one night or more to hospitals within the NHS Trust. The index admission that resulted in referral to the memory clinic was not counted.

In the dataset provided, chronic comorbidity data were not able to be separated from acute complications, therefore these data were not able to be used. Hospital admission data in the 12 months prior to the index admission were used as an indication of morbidity, as higher levels of morbidity are associated with higher levels of emergency admission (Purdy, 2010). The lack of control a researcher has over the type and quality of data collected is a recognised limitation of studies using secondary data (Lowrance 2003).

3.7.4.1 Diagnostic outcome

The outcome of assessment in the clinic database recorded the diagnosis given following assessment or that the patient was cognitively intact if there was no concern following assessment. It also recorded if patients were not assessed and why. If the outcome of the assessment was a dementia diagnosis, this was coded by sub-type of dementia for the three most prevalent sub-types: Alzheimer's disease, Vascular Dementia and Mixed Dementia types. Due to the small numbers of other sub-types and those in which a sub-type was not given, these were coded together as "other dementia diagnosis". A diagnosis of cognitive impairment, mild cognitive impairment or vascular cognitive impairment were coded together as "cognitive impairment". Where a physical or psychiatric diagnosis was given following assessment, rather than a dementia or cognitive impairment diagnosis, this was coded as "non-dementia diagnosis". All people referred to the memory clinic (or a carer/ relative) were contacted by the clinic to arrange assessment appointments. Patients who refused assessment

following contact from the memory clinic or who arranged appointments and then did not attend were coded together as “Refused assessment/ did not attend”. If the assessment did not take place because the person was too unwell, had died between referral and contact from the clinic or could not be contacted to arrange an appointment, they were coded together as “unable to assess”.

3.7.5 Data Analysis

Data analysis was carried out using SPSS v25 (IBM Corp, 2017). Bivariate analyses of the data were conducted, and characteristics of the different referral groups were compared using Chi square tests (or Fisher’s exact test when appropriate) for nominal variables and ANOVA for continuous variables. When the Chi square/ Fishers exact statistic was significant, standardised residuals were used to determine where the difference lies (using a cut off of +/- 2) (Sharpe, 2015). Binary logistic regression was performed to explore factors associated with the likelihood of a dementia diagnosis and factors associated with likelihood of survival at 12 months post referral for those diagnosed with dementia. The bivariate analysis was used to explore the relationship of independent variables with the outcome. Any variables significant at the level of $p<0.20$ were included in the multivariable analysis described below. A backward selection method was used, whereby all the variables detailed in the models below were included in the full model. Variables with a p value of <0.05 were considered significant and at each step non-significant variables were removed, and the analysis repeated until only significant variables remained in the final model.

3.7.5.1 Model 1: Identification of factors associated with a diagnosis of dementia

A dementia diagnosis was the dependent variable. The four categories of dementia diagnosis – Alzheimer’s disease, Vascular Dementia, Mixed Dementia and Other Dementia were coded as Dementia. An assessment that resulted in a diagnosis of cognitive impairment, a non-dementia diagnosis or cognitively intact were coded as No Dementia. Independent variables examined included age, gender, ethnicity, referral source and hospital admissions in the 12 months pre-referral. Those unable to be assessed or who refused assessment were excluded. Number of hospital admissions post referral and survival at 12 months were not included in this model as they occur after diagnosis.

3.7.5.2 Model 2: Identification of factors associated with survival at 12 months post referral for those diagnosed with dementia

Survival at 12 months post referral was the dependent variable. Independent variables examined included age, ethnicity, referral source, type of dementia, severity of dementia at diagnosis, hospital admissions in the 12 months pre-referral and hospital admissions in the 12 months post-referral.

The findings of the quantitative exploration can be found in Chapter Six.

3.8 Phase Four: Integration of findings

The aim of the mixed method design in this study was for the qualitative, quantitative, and systematic review findings to complement each other to provide a more complete understanding of why people may not seek help for a dementia diagnosis. As described earlier in section 3.2.2 the results of each phase were analysed separately and were then integrated in a separate phase of analysis. It is recognised that there are challenges and complexities in merging different sets of data, particularly when they relate to different aspects of a phenomenon and are not seeking to study the same variables, as was the case in this study (Brannen and O'Connell, 2015).

3.8.1 Integration of findings

The placing of findings side by side in a joint display allows direct comparison of concepts or themes within the data and provides a strong starting point for integration (Bazeley, 2018). However, detailed guidance on how to integrate data in joint displays has been lacking, and Johnson et al (2019) developed the Pillar Integration Process to rectify this. They describe their process of integration as one which minimises observer bias and maximises opportunities for synthesis. The Pillar Integration Process has four stages, and these are detailed in table 3.7 along with how they were implemented in the integration of findings in Chapter Seven.

Table 3.7 Stages of the Pillar Integration Process and implementation in this study

Stages of Pillar Integration Process	**Implementation in this study**
1. Listing – raw data, coded or grouped data are listed in QUAL and Quan columns	Three columns created for QUAL, Quan and systematic review data. Themes and detail of the data that comprised the themes listed for QUAL and systematic review included. Significant findings related to the characteristics of people referred from different sources listed in Quan column.
2. Matching – data in the columns are moved so that similar data are aligned horizontally, and rows reflect patterns, parallels or other relational qualities between QUAL and Quan data. Some columns may be left blank where no match in the data is found	Data for the three columns were moved within each column so that rows represented data that confirmed, enhanced, or diverged from one another
3. Checking – data are checked for quality purposes ensuring rows are appropriately matched, gaps are double checked and verified to ensure no raw data can provide a match	Data were checked and where gaps existed a re-check of available data from each phase was made to ensure nothing had been missed
4. Pillar Building – a central column or pillar is inserted. Findings on each row are compared and contrasted, and inferences and possible explanations for the patterns that have emerged are conceptualised. An integrated theme that represents this is inserted in the pillar column. When viewed together the integrated themes can be used to form a meaningful narrative of the integrated data.	A fourth column was inserted to the right of the three existing columns as a central column was not possible. An integrated theme name was inserted in this column and a narrative to explain how the data resulted in the theme was included below the table.

3.8.2 Analysis of integrated themes

As discussed earlier, the use of abductive and retroductive logic are key elements of a critical realist analysis that aims to identify underlying causal mechanisms. Following the integration of data from the three study phases and identification of integrated themes, the researcher considered a broad range of theories and concepts that might help to explain the study findings. The researcher then chose theories and concepts representing three broad areas that were reflected in the integrated themes, to use in the abductive reasoning. This re-description and recontextualization of the findings considering relevant theories and concepts provided a discussion of the most plausible explanations for carers not seeking help for a dementia diagnosis. A retroductive reasoning process followed using the technique of counterfactual thinking. This technique is a process of considering "what something is in relation to what it is not" (Danermark et al 2019:122). By considering the presence and absence of factors, what is necessary and what is contingent for something to happen, a proposition can be made about the underlying structures and mechanisms, and the context in which other mechanisms may interact with these, to produce an outcome or event (Danermark et al 2019). In Chapter Eight this was done by considering what might facilitate help seeking for a dementia diagnosis. The retroductive propositions of the interaction between structures and their mechanisms, context mechanism (other mechanisms) and the outcome they produced were represented in graphical form using an example from Eastwood et al (2016)(Figure 3.5).

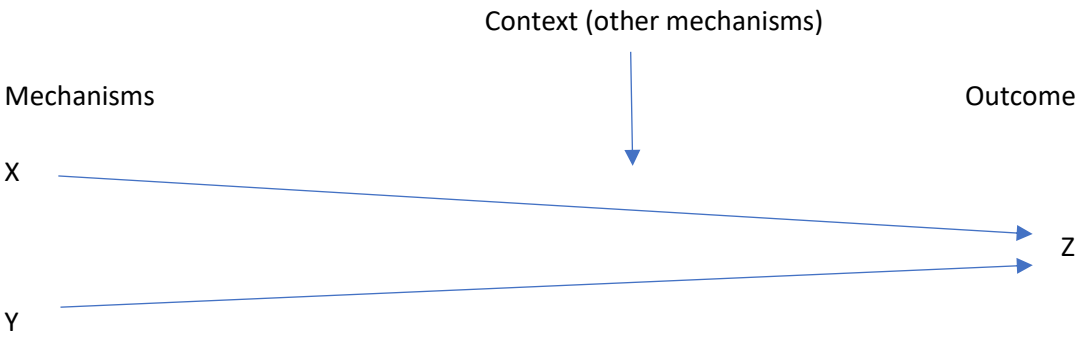


Figure 3.5 Graphical representation of the proposition resulting from abductive and retroductive reasoning, depicting the mechanisms (or context) which interact with the mechanisms of social structures to produce an outcome (Eastwood et al 2016).

Critical realist studies aim to make theoretical generalisations rather than generalise to a specific population. The propositions made by the retroductive analysis process and the

resulting model of how help seeking might be prevented are considered a theoretical generalisation which can be applied in future research to other populations of carers to test its applicability. If future studies provide evidence to the contrary, then this should prompt further retroduction to identify other causal mechanisms that may be preventing the mechanism in the model to be triggered (O'Mahoney and Vincent 2015).

3.9 Quality assessment of the study

Evaluating the quality of a study is important to add credibility to the study findings (Cresswell and Plano Clark 2018). There are numerous terms used to discuss quality in relation to research, such as validity, rigour, trustworthiness, and credibility, but O'Cathain (2010) favours the term *quality* in relation to the evaluation of mixed methods studies. The theoretical generalisations made by critical realist studies are considered to be more enduring than generalisations about populations, but to ensure quality in critical realist studies, importance is also placed on the way data are used to support interpretations and conclusions (O'Mahoney and Vincent 2015, Maxwell 2012). This particular focus on quality is considered to overcome issues related to quality in mixed methods research, which often relate to methods of data collection and inference based on very different assumptions in quantitative and qualitative studies (Maxwell and Mittapalli 2010). However, the ways in which a critical realist study might ensure any plausible threats to conclusions being drawn are mitigated, is not clear in the literature (Maxwell and Mittapalli 2010).

Ensuring quality in mixed methods studies has been widely discussed, and the framework devised by O'Cathain (2010) has attempted to consolidate other frameworks and considerations in the mixed methods literature. It also contains a domain of interpretative rigour which may address the issues related to critical realist studies. This framework has been used to demonstrate how issues of quality were addressed in this study. The framework consists of eight domains and each will be discussed considering this study below.

3.9.1 Domain 1: Planning Quality

This domain addresses how well a study has been planned, to include the foundational element, rationale transparency, planning transparency and feasibility. An overview of the existing literature related to help seeking for a diagnosis of dementia was presented in Chapter Two and Phase One of the study was a comprehensive systematic review of the literature of the barriers and facilitators to help seeking for a diagnosis of dementia from the perspective of

people living with dementia and their carers. Together these have helped to identify a gap in the literature that this study aimed to fill, and the systematic review contributed important data to the overall analysis. This chapter has set out a clear rationale for the use of a mixed methods approach and clearly described the assumptions of critical realism and its influence on the study design. As an unfunded PhD study, this has been a feasible undertaking.

3.9.2 Domain 2: Design Quality

Domain two consists of design transparency, design suitability, design strength and design rigour. Within this chapter the convergent design of this study, with a purpose of complementarity and a QUAL + quan design has been described along with how data integration has taken place. The four phases are appropriate to achieve the study aim of understanding why people may not seek help for a dementia diagnosis. The systematic review provided a sound evidence base on which to compare and contrast the findings of phase two and three. The qualitative exploration in phase two addressed depth in the experiences of carers, and the quantitative exploration in phase three addressed breadth in the characteristics of the population. As the study aimed to research a population who have not been well studied, the study's strength lies in its complementary design to determine both the characteristics and experiences of this population. The only compromise to the study's rigour is that the voice of people living with dementia could not be included due to recruitment difficulties.

3.9.3 Domain 3: Data Quality

This domain reflects data collection and analysis and includes data transparency, data rigour, sampling adequacy, analytic adequacy and analytic integration rigour. This chapter has described in detail the data collection and analysis of the four study phases. It is not considered that any phase has been compromised for being part of a mixed methods study, as all phases were undertaken as planned. Despite recruitment difficulties, data saturation was reached in the qualitative phase and although the sample size in the quantitative phase was limited by the availability of data, this was sufficient to draw some inferences about the study population. Appropriate data analysis techniques were used for each phase and then another level of analysis was undertaken when integrating the findings to ensure analytic integration rigour.

3.9.4 Domain 4: Interpretive Rigour

This domain relates to whether the conclusions drawn from the study are based on the findings, and addresses Maxwell and Mittapalli's (2010) concerns that any plausible threats to the conclusions being drawn are mitigated. The domain includes interpretive transparency, interpretive consistency, theoretical consistency, interpretive agreement, interpretive distinctiveness, interpretive efficacy, interpretive bias reduction and interpretive correspondence. The findings of each phase of the study have been reported separately with a clear integration process that demonstrates how the findings of each phase contributed to the final analysis and discussion. As the whole study was undertaken by one researcher, no aspect of the study was considered more important than the others. In addition to the review of the findings and inferences by the supervision team, each study phase was peer reviewed as part of the publication process. Where there may be other possible interpretations of the findings these are considered, and the distinctiveness of the interpretations are justified. An additional way to establish interpretive rigour would have been for carers and people living with dementia to have been involved in the interpretation of the data and a review of the overall findings. Unfortunately, this was not feasible due to time constraints. However, the researcher employed a reflexive approach throughout data collection and interpretation, and it was felt that the final retroductive analysis derived from this study answered the research question, and the study aim was met.

3.9.5 Domain 5: Inference Transferability

This domain relates to the transferability of findings from each phase of the study and from the meta-inferences of the whole study. The sample in the quantitative phase was described in detail to allow a consideration of the generalisability of the findings to similar populations. Limited demographic information was available for the qualitative sample which makes consideration of the transferability of findings more difficult. However, as a critical realist study, theoretical generalisation was the overall aim, and this was achieved.

3.9.6 Domain 6: Reporting Quality

This domain relates to report availability, reporting transparency and yield. The methods and findings of each phase have been reported using the appropriate reporting guidelines – PRISMA guidelines for the systematic review, COREQ guidelines for the qualitative exploration

and STROBE guidelines for the quantitative exploration. It is clear how each phase contributes to the integrated findings and how the findings relate to the abductive and retroductive reasoning in Chapter Eight.

3.9.7 Domain 7: Synthesizability

This domain relates to whether the published findings of the study would be considered for inclusion in a systematic review of the topic using a tool, such as the MMAT used in the systematic review of this study. As the three study phases have been submitted for publication separately, an online copy of the thesis may also be accessed and included in future reviews, so it was appropriate to consider the whole study when applying the appraisal tool. When applying the MMAT criteria (Appendix 5) to each phase of the study, it is considered that all the criteria have been met.

3.9.8 Domain 8: Utility

The utility of a study, whether from a policy, practice or theory point of view is difficult to determine at this early stage. It is hoped that the findings contribute to the growing body of knowledge in how people with dementia can be supported through their diagnostic journey and beyond. Where the study has made specific recommendations, every effort will be made to ensure these are disseminated appropriately and avenues of funding for further research and development sought as needed.

3.10 Ethical considerations

Ethical principles should apply to all stages of a research study, from the initial design, through recruitment, data collection, analysis, and dissemination of results. The NHS Health Research Authority (HRA) has published a UK Policy Framework for Health and Social Care Research (NHS Health Research Authority, 2017) which incorporates all types of research undertaken in or with the NHS. This study received ethical approval from the HRA, recruited participants through the NHS and an NIHR database and used an NHS database and patient records. This section will address the core principles of the HRA (2017) framework as they apply to this study. The HRA framework (2017) consists of 15 principles related to the conduct and management of research in health and social care (Appendix 16).

A detailed protocol for the qualitative exploration in phase two (Appendix 17) was produced and was externally peer reviewed. An application was made through the IRAS system for full ethical approval from an NHS Research Ethics Committee. Approval was granted to interview carers and people living with dementia, including those who lack capacity to consent (Appendix 18). A protocol for the quantitative exploration in phase three was produced (Appendix 19) and an application made through the IRAS system for HRA approval, as full NHS Research Ethics Committee approval was not required. Approval was granted to use anonymised data from the memory clinic database and related electronic patient records (Appendix 20). Research indemnity and insurance were confirmed by the University, and confirmation of capability and capacity from the relevant NHS research and development departments was subsequently gained. Information about the study was published on the HRA website.

Although the researcher would be considered a novice, the supervision team were very experienced in both quantitative and qualitative research within health and social care settings. The researcher attended research methods seminars for doctoral students at the university and undertook the following online NIHR Good Clinical Practice (GCP) courses – Introduction to Good Clinical Practice (Secondary care), Informed Consent with Adults Lacking Capacity and JDR Researcher Training. The study was subject to The City, University of London Governance framework for Good Practice in Research and the School of Health Sciences Research Governance Policy to ensure regulation, monitoring and quality assurance.

3.10.1 Public and Patient Involvement

Patient and public involvement (PPI) has been shown to improve the relevance, appropriateness and quality of research in health and social care and is increasingly being supported as an essential aspect of research approval and reporting (Brett et al 2012). PPI can take place at all stages of the research process, although long term involvement in a research project is not without challenges (Miah et al 2019). PPI involving people living with dementia identifies the important role they and their carers can play in ensuring that participant information sheets, consent forms and other aspects of research design are appropriate for participants (Miah, 2019). In this study the topic guide for the qualitative phase was peer reviewed by three academics external to the supervision team – two leading dementia research professors and one professor of psychology specialising in qualitative research as part of the ethical approval process. The topic guide, participant information sheets and consent

form were reviewed by people living with dementia and their carers at an Alzheimer's Society dementia café in the same borough as one of the participant identification centres. Their opinions were - that the topic itself, questions and prompts proposed were not too sensitive or intrusive and they would be happy to discuss them in a research interview. They were invaluable in giving their opinions about their preferences when taking part in an interview. This included having short questions that were easy to understand and being able to answer in their own words. Some expressed a preference for being interviewed in a familiar place like the dementia café, rather than a stranger coming to their house. At the time of visiting the dementia café the researcher had still planned to include people living with dementia in the qualitative interviews, they suggested a shorter easier to read version of the information leaflet, which was produced, and carers were positive about giving their assent, as consultees for people with dementia who lacked capacity, to be able to participate.

3.10.2 Risks and benefits to participants

It is recognised that participating in interviews can have several benefits for participants including feelings of relief in being able to express how they feel to someone who is engaged and ready to listen, validation of their feelings, an increased sense of self-esteem and purpose and feeling empowered by having their voice heard (Hutchinson et al 1994). Knowing that sharing their story may help others in the future is often a reason for people to participate, indeed in this study many carers hoped others would not have to go through the some of the experiences they had (Clarke 2006, Corbin & Morse 2003).

There are concerns that talking about or reliving difficult life experiences during interviews may cause psychological distress to participants (Clarke 2006), and that in reliving their caregiving experiences, carers may feel a sense of failure, disrupting their coping processes (Funk and Stajduhar, 2009). Participants may also worry about revealing more than they intend to within an interview and later regret this (Corbin & Morse 2003). Engaging people well during their interview can help to ensure they exercise control over the process, deciding what they do and do not talk about and how things are said (Hutchinson et al 1994, Corbin & Morse, 2003). Concerns about upsetting participants or breaches in confidentiality when sharing personal information also assume that the risk of this happening is greater in a research interview than if the person were discussing the topic with family or friends (Corbin & Morse 2003). A researcher may be more interested in how the person feels, than family and

friends would be, and be empathetic as well as having rigorous processes in place to prevent breaches in confidentiality (Corbin & Morse 2003).

It was proposed that the benefits of participating in this study, both for the individual carer and for the research purpose of understanding why people may not seek help, outweighed any risk of distress. Carers did talk about difficult aspects of their caring relationships, sometimes expressing anger, regret and sadness, particularly if the person with dementia had died, but they always initiated these aspects of the conversation themselves and wanted to continue to talk about how they felt. The researcher was mindful of acknowledging their feelings and the contributions they had made as a carer and no carer became upset or distressed to a point where the researcher offered to stop the interview or was concerned that they needed additional support. However, being aware of the sensitivity of the topic and the possibility that carers may become distressed, the researcher had an appropriate plan in place to manage such situations. The researcher had extensive experience discussing diagnosis of dementia with people who were being given a new diagnosis, along with their carers, from their previous clinical role, including discussing sensitive topics, such as end of life care, with carers of people with dementia. As such the researcher felt confident asking questions and guiding conversations in a manner that does not provoke distress and in interpreting both verbal and non-verbal signs of distress in others and responding appropriately.

In the event that a participant did become upset or distressed during the interview the researcher planned to support them to express their emotions, if they wished, and give them the option to take a break or discontinue the interview. Haarh et al (2014) suggest that we should trust the participant to choose whether they let go of their natural defence mechanisms and as researchers we should be responsive to individual situations, guided by bioethical principles and our own internal moral voice as a healthcare professional. If the person had continued to appear upset or distressed after the interview had ended, then it was planned to refer the person back to the liaison team at the hospital, if they had been recruited this way, for community follow up to be arranged. If they preferred, and for participants recruited via JDR, they would have been offered information on how to access further support from their local Alzheimer's society, Dementia Care team or national dementia helplines. However, this was not necessary for any participant.

When discussing sensitive topics with vulnerable people it is important to be prepared in the event that a participant discloses information that suggests either they or the person they care

for may be at risk of harm, despite how rarely this happens in practice (Johnson and Rowland, 2014). Although the likelihood of safeguarding issues arising during this study was low, two possibilities were planned for– that the person may be at risk of harming themselves and that they may be at risk of harming others.

If a carer disclosed information suggesting they were at risk of harming themselves, the researcher would have expressed concern about their disclosure and asked whether they had talked to anyone else or sought support for how they were feeling. They would have been encouraged to seek support or talk to significant others about how they felt, and an offer to pass on information to the liaison team at the hospital that had recruited them would have been made, for an appropriate referral to the community mental health team, dementia care team, Alzheimer's society etc. For carers recruited via JDR they would have been offered support in making a self-referral to an appropriate team. Pre-prepared information about these sources of support, would have been left with participants along with their contact details. The offer to contact a friend or family member if they wanted immediate support would also have been made as appropriate.

However, if any participant disclosed information that suggested they were at risk of harming others (either an individual or a wider public risk), again the researcher would have expressed concern about their disclosure and encouraged them to seek support or talk to significant others about how they felt. The researcher would also have explained that they had a duty to protect the person(s) at risk of harm. This would have involved discussing the disclosed information with the hospital trust or local authority safeguarding team to decide if a referral needed to be made on their behalf to either the community mental health team, dementia care team, social services or police. In these circumstances the researcher would have had to break confidentiality to access the help for the person. As part of the informed consent process the circumstances in which confidentiality would be breached, the information that would need to be disclosed and to whom and that this was not optional was made clear to the carer. If a breach of confidentiality had been required, the researcher had planned to keep the carer informed of any discussions or referrals made on their behalf.

The secondary use of anonymised data in research also raises some ethical concerns. It is generally considered that using anonymised data without consent does not result in harm to participants, but some authors disagree and consider that harm can occur even if the participant is unaware of it (Robling et al 2004). Due to the highly personal and sensitive nature of health data it may never be possible to completely anonymise it (Spencer et al 2016,

Kalkman et al 2019a). There is a societal expectation that people have a right to know if and how their data are being used, but there is also considered to be a duty to share health data for the greater benefit of society and the needs of the two should be balanced (Spencer et al 2016, Kalkman et al 2019a).

In a recent review of patient and public attitudes towards the use of health data for scientific research there was widespread support from the public, with many benefits to the use of data being identified (Kalkman et al 2019b). However, concern was also expressed about the potential risks which might arise from breaches in confidentiality, data security, access, and control of data. This could be because the general public are unaware of the safeguards and legislation regarding use of data and the research process generally (Robling et al 2004) and certainly Kalkman et al's (2019b) review suggests that transparency and control over who data is shared with, was an important prerequisite to consenting for data use.

In the qualitative and quantitative phases of this study the management of research data followed the strict guidance of the Data Protection Act and General Data Protection Regulations (Data Protection Act 2018), as well as university data management policies to mitigate against risks related to the use of data. In the qualitative phase of the study all audio files and word documents of interview transcripts were stored on a password protected computer, which only the researcher had access to. Pseudonymised transcripts used in NVivo software were shared only with a member of the supervision team to facilitate a review of the coding as part of the quality assessment of this phase of work. The personal contact details of carers were stored separately on a password protected computer or were contained within the JDR website which requires a login set by the site administrators. In the quantitative phase of the study the data were anonymised by the Business Intelligence Unit in the trust and transferred to the researcher via a secure NHS.net email. All the original data and subsequent coded datasets were stored on a password protected computer, that could only be accessed by the researcher.

3.10.3 Confidentiality and Anonymity

Understanding the limits of confidentiality and how research data will be used is an important part of the informed consent process. Procedures for consent should be proportionate to the study (The British Psychological Society, 2014) and the data being collected, and in this study the School of Health Sciences consent form template was adapted for use in the qualitative phase. Participants were given time prior to the start of the interview to re-read the

information leaflet which contained details on what they were being asked to do, their ability to withdraw from the study at any time and what would happen to their data after the interview had finished. They were then given time to read the consent form and ask any questions. All participants gave written informed consent, with one copy of the signed form kept by the participant and one by the researcher.

Seeking consent to use previously collected data, as in the quantitative phase of this study presents some practical challenges. Depending on the length of time since the data was collected it may not be possible to contact patients who have moved or died (Lowrance 2003) and in the case of this study patients may no longer have had the capacity to consent. Obtaining contact details for all patients may be difficult, and in this study, contact details could only have been obtained for those who had had an admission to hospital. Full contact details were not recorded in the memory clinic database, so those referred by their GP who had never attended the hospital would not have been contactable. Not including these patients would have had potentially skewed the results, as would only including the self-selecting group of patients who would consent to having their data used (Lowrance 2003). However, the use of anonymised data collected as part of routine care does not require individual consent or NHS Research Ethics approval. HRA approval was sought to use the data in this study.

Anonymisation of data is the best way to reduce the potential for harm and ensure confidentiality and privacy. Breaches of confidentiality in research should be limited to exceptional circumstances and concerns around confidentiality are usually related to ensuring that no one other than the researcher knows who the participants were (Kaiser, 2014). There is a concern that, in the analysis and reporting of in-depth interviews, the use of verbatim quotes to illustrate and justify findings or themes, may compromise external confidentiality. External confidentiality refers to ensuring that participants cannot be identified from any published results or findings (Tolich 2004). In this study, as the interviews were transcribed, any potentially identifiable words or phrases were replaced with pseudonyms. This included removing any names from the transcript and replacing them with a pseudonym or a tag that typifies the person, for example daughter, husband, friend, neighbour. Any exact geographical locations which were used to identify someone were also replaced with a meaningful descriptive term. Internal confidentiality refers to ensuring that participants in the same study are unable to identify each other, based on published results or findings (Tolich 2004). This is of particular concern where one participant may be connected to another participant in the study (such as carer and cared for person) or people belonging to a particular group are being

interviewed about the same event or experience. As participants in this study were drawn from the whole of the Greater London area and their diagnostic experiences were over a long period of time, it is very unlikely that participants knew each other, so a threat to internal confidentiality was a not a particular concern. Following the procedures described above to ensure external confidentiality should be enough to ensure internal confidentiality.

In the use of secondary health care data there are two aspects of anonymisation that may cause problems – data linking and reversible anonymisation (Lowrance 2003). The linking of data from multiple databases may require more personal data to accomplish this, and even when anonymised there may be a greater chance of the data remaining identifiable. Only one database was used in this study, supplemented by additional data from electronic patient records and DBS. It was not considered that the amount and type of data extracted could result in data being linked to identify a patient. Reversible anonymisation or key coding allows for the possibility of data to be re-identified for further research or audit purposes. As this may be desirable in some studies, best practice would be for the researcher accessing the anonymised data to not be able to access key codes or identifiers for patients (Lowrance 2003). In this study the ability to re-identify the data was not stipulated so any re-identification could only be done by the business analyst who extracted the data. The use of anonymised data is considered out of the scope of General Data Protection Regulations (Data Protection Act 2018) but hospital trust GDPR procedures ensured that the process of anonymisation was carried out appropriately.

3.10.4 Researcher safety

In considering ethical issues, it is important that those relevant to the researcher themselves are also considered. This includes not only the physical safety of the researcher when visiting participants in their own homes or workplaces, but also any potential psychological and emotional risk that may arise from being exposed to distressing information during data collection and analysis (Braun and Clarke, 2013). The university policy at the time was to follow the guidance provided in the Code of Practice for the Safety of Social Researchers (Social Research Association, 2001). In accordance with this advice, where interviews were taking place during office hours, the departmental administrator knew the date, time and address of the interview and out of office hours a member of the supervision team was aware of the date, time and address of the interview taking place. Neither the administrator nor the supervisors were able to make connections between the interview timings and settings and the data produced by the interviews to ensure confidentiality.

3.11 Reflexivity

Reflexivity can be described as “a continual internal dialogue and critical self-evaluation of the researcher’s positionality” (p2) and it is essential that the researcher considers how their own experiences and thoughts influence a study design, data collection and interpretation (Finefter-Rosenbluh, 2017). In this section I will critically reflect on how my own beliefs about diagnosis, my lack of research experience and my relationship with the recruiting teams had the potential to influence the study and how these were mitigated throughout with constant reflection.

3.11.1 My own beliefs about diagnosis

The original idea for this study had arisen from my clinical work as a nurse consultant working within an acute hospital assessing and diagnosing people identified to have cognitive problems on admission to hospital. I had been equally amazed by how long some people had symptoms before their hospital admission without ever seeking help and how being assessed and receiving a diagnosis was not always seen as necessary or a priority by some people living with dementia and their families. My clinical, biomedical perspective had led me to believe that diagnosis was not only a person’s right, but necessary and beneficial for all. On commencing my PhD studies I was encouraged by a supervisor to question these beliefs and consider whether diagnosis is always of benefit to everyone and as such throughout my studies I have often moved back and forth between a position of diagnosis being beneficial to all and a position where diagnosis may be more harmful and not being necessary for everyone. Moving from my clinical role to an academic role within the university part way through my studies and having a supervision team with varied levels of dementia experience, from an academic and clinical perspective, has helped me to find a balanced position on the benefits of diagnosis. But I believe that continuing to have a questioning perspective on this is important so as not to prioritise the experiences of some carers over others. During my interviews with carers I was very aware that I did not want to advocate for a particular position on diagnosis and remain as neutral as possible so that they could freely express their thoughts. The semi-structured nature of the interviews helped this as the prompts were related to what carers were telling me, but it is important to acknowledge that subconsciously I may have prompted or probed more deeply when carers were expressing thoughts that matched more closely with my own. Each individual carer experience that I heard also had the potential to influence my own beliefs. There were times when carers expressed great difficulties and upset post diagnosis but then

others where I could see that an earlier diagnosis would have helped them. After one interview I found myself questioning whether the person living with dementia had been given the right diagnosis and even mentioned this to the psychiatric liaison team member who had recruited them for me. On reflection, I had overstepped my role as an outsider researcher in doing this and my previous clinical role was influencing my interpretation of the carer's experience. After this early experience, I took time after each interview to consider how these individual carer experiences made me feel and in some ways it was fortunate that the interviews did not all take place in a short space of time, as this gave me the opportunity to consider each experience but then be able to put this to one side for the next interview. My beliefs about diagnosis were quite ambivalent by the time the interviews had finished. Beginning formal analysis of the data after all the interviews had finished helped to ensure my beliefs had limited influence on the data analysis and interpretation. However, I continued to be very conscious of this as I analysed and interpreted the data and the review of my coding by one of my supervisors and discussion of the themes and supporting data with my supervising team helped to ensure I was providing an accurate and balanced account of carer's experiences. In critical realism researchers should commit to effecting emancipatory change where possible (Ackroyd and Karlsson 2014). As the carers interviewed in this study had been through the diagnostic process, the aim was to understand their experiences rather than encourage them to seek help, but in making recommendations at the end of the study and ensuring that the findings of the study are disseminated this can be realised. However, I continued to be conscious that the recommendations I made did not prioritise one set of beliefs over another, and I am content that this was achieved.

3.11.2 My lack of research experience

My inexperience as a researcher will also have had an influence on the study. My initial intention had been to interview people living with dementia as well as their carers, and I put considerable effort into gaining ethical approval to interview people living with dementia who may lack capacity to consent. It may have been naïve, given the late stage of dementia that people identified during a hospital admission are often at, that they would have been able to participate. However, in my clinical role I had spent time with people throughout their assessment and diagnosis, and very much felt that they would be able to participate in an interview. As I began the study whilst in my clinical role, my original plan had been to recruit the patients I was seeing and had I stayed in this role this may have been possible. I had not fully considered how much more difficult recruiting participants would be through other staff

members and with more experience I might have explored alternative recruitment strategies or made the decision to interview carers only at an earlier point in the study. However, the absence of the voice of the person living with dementia in dementia research is often rightly criticised, and I have wrestled with the fact they are not a part of my study throughout. As a result at many points in my study I have had to reflect on the where my focus was and remind myself that the voice and experience of the carer was equally important in this context and as such was a valid topic of study. In making recommendations at the end of the study I was conscious that this was an opportunity to ensure that the voice of people living with dementia in their diagnosis process could be heard and I am content that I have been able to achieve this. I was also reminded of my lack of experience as a researcher when transcribing and coding the interview data, as I identified opportunities within the interviews where I could have probed deeper to gain a better understanding of their experiences. But when conducting the interviews, particularly the early ones, I was nervous, conscious that I was in the carer's home and already felt that I was being intrusive in asking about a difficult and sensitive situation. At times I was questioning the decisions they had made and did not want to push the questioning to a point where they no longer wanted or felt they could be honest about their experiences. I gained some confidence as the interviews progressed but on reflection my lack of interviewing experience could have resulted in less rich data than might have been possible.

3.11.3 My relationship with the recruiting teams

Recruitment for the study was challenging, and although the main reasons for this were likely to have been related to the people living with dementia and carers I was trying to recruit, my relationship with the recruiting hospital teams may have had both a positive and negative influence. In my previous clinical role, I had been responsible for setting up the nursing and therapy element of the three psychiatric liaison teams and had been involved in the recruitment of all the staff including the manager of the teams. This is likely to have influenced their willingness to offer their help when I initially approached them. Before recruitment commenced, I spent time with the teams discussing the process and any concerns about recruitment they may have, and they did not express any strong concerns. On reflection it is possible that, although I no longer worked at the trust, they still saw me as a senior member of staff and consequently did not feel comfortable questioning me or raising concerns. Rather than do this, they may have chosen to agree to help but then not actively identify or approach potential participants. The exception to this was Team A, however my clinical connection to this team is likely to have influenced why they were more proactive than the others. I had

previously managed the team leader of Team A and had a close, friendly relationship with her, so it is likely that this was the reason she was more keen to help and encouraged her team members to do the same. My ability to maintain regular contact with the teams was also a factor. Aspects of my academic role meant that I visited the hospital where team A were based on a regular basis, visiting the other sites was much more difficult, with communication being largely by email. Although maintaining more regular, in person contact with all the teams could have positively impacted on recruitment, this was not possible from a practical or time perspective. This is a disadvantage of studying for a PhD part time, whilst carrying out a full-time role either clinically or in academia. Time spent on my PhD studies during the working week had to be fit around ensuring my work role commitments were met, and this was often a challenge.

3.12 Summary

This chapter has outlined the convergent mixed method study design used and how this was influenced by critical realism. Details of how all four study phases were undertaken have been given and the results of the systematic review can be found in Chapter Four, the results of the qualitative phase in Chapter Five and the quantitative phase in Chapter Six, with the integrated results in Chapter Seven. This chapter has included the researcher's reflections on their own position in the study design and conduct.

Chapter 4: Persistent barriers and facilitators to seeking help for a dementia diagnosis. A systematic review of 30 years of the perspectives of carers and people with dementia

The overview of the body of evidence related to help seeking in Chapter Two identified that despite numerous studies of the barriers and facilitators to help seeking for a diagnosis of dementia, from the perspective of carers and people living with dementia, these had not been systematically reviewed. Phase One of this study was a mixed studies systematic review of the barriers and facilitators to seeking help for a dementia diagnosis. Thirty-two studies exploring the perspectives of carers and people living with dementia over a thirty-year period were included and ten barrier themes and three facilitator themes were identified. The synthesis of studies demonstrated the complexity of the help seeking process, with multiple barriers compounding a delay to diagnosis and more than one facilitator often required for help seeking to take place. The findings of the systematic review were compared and contrasted with the findings of the qualitative and quantitative phases of the study in Chapter Seven. This chapter is presented in the form of an article for publication. The article includes a brief introduction to the topic and methods which have been covered in more depth in Chapter One and Chapter Three. The findings of the review are presented followed by a discussion of the findings. The final section of the chapter is an overview of additional studies eligible for inclusion published after the original review was published. The systematic review was accepted for publication in *International Psychogeriatrics* and the details of the publication are:

Parker, M., Barlow, S., Hoe, J., Aitken, L. (2020) Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics*. 32 (5) pp611-634

STATEMENT OF CO-AUTHORS of JOINT PUBLICATIONS

TO WHOM IT MAY CONCERN

Title of publication: Persistent barriers and facilitators to seeking help for a dementia diagnosis. A systematic review of 30 years of the perspectives of carers and people with dementia

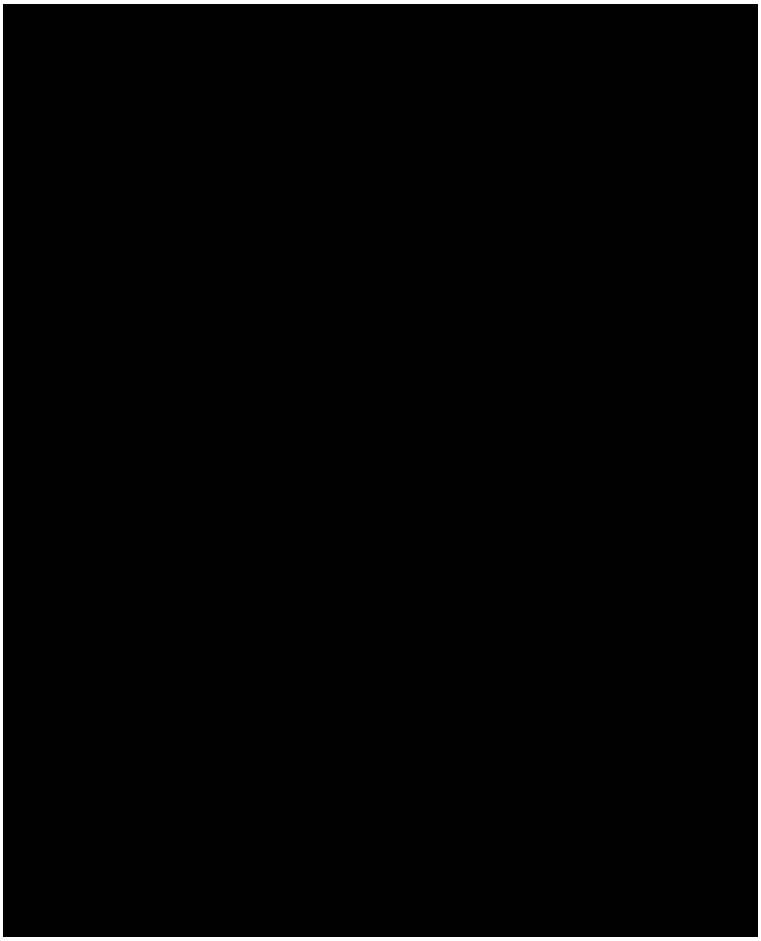
Name of candidate: Michelle Parker

Title of research thesis: We need to talk about dementia: Stigma and the role of the social network in preventing help seeking for a diagnosis of dementia

Name of first supervisor: Professor Leanne Aitken

We, the undersigned, co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.



Statement indicating the candidate's contribution to the publication
The candidate's contribution included:

- Carrying out all searches and removing duplicates
- Reviewing all studies for eligibility
- Quality appraisal of all studies
- Data extraction from all included studies
- Synthesis of the data
- Writing and revision of the manuscript

The review and writing of the paper were conducted with methodological and editorial advice from Professor Leanne Aitken, Dr Juanita Hoe and Dr Sally Barlow.

Abstract

Objective: To identify barriers and facilitators to help seeking for a dementia diagnosis from the perspective of carers and people with dementia.

Design: A systematic review of the literature was conducted according to PRISMA guidelines (PROSPERO protocol registration CRD42018092524). Nine electronic databases were searched for qualitative, quantitative, and mixed methods primary research studies. Two independent reviewers screened titles and abstracts, full texts of eligible studies and conducted quality appraisal of included articles. A convergent qualitative synthesis approach was used.

Results: From 7496 articles, 35 papers representing 32 studies from 1986 – 2017 were included. Studies originated from 13 countries across 4 continents. Barriers and facilitators were reported predominantly by carers. A small number of studies included people with dementia. Barriers included *denial, stigma and fear, lack of knowledge, normalisation of symptoms, preserving autonomy, lack of perceived need, unaware of changes, lack of informal network support, carer difficulties* and *problems accessing help.* Facilitators included: *recognition of symptoms as a problem, prior knowledge and contacts* and *support from informal network*.

Conclusions: Studies from a 30-year period demonstrated that barriers to help seeking persist globally, despite increasing numbers of national dementia policies. Barriers and facilitators rarely existed independently demonstrating the complexity of help seeking for a diagnosis of dementia. Multiple barriers compounded decision-making and more than one facilitator was often required to overcome them. Multi-faceted interventions to reduce barriers are needed, one approach would be a focus on development of dementia friendly communities to reduce stigma and empower people with dementia and carers.

Keywords: Dementia, diagnosis, help seeking, barriers, facilitators

1. Introduction

Dementia is a progressive neurocognitive syndrome characterised by deterioration in cognitive function that significantly affects a person's ability to maintain activities of daily living (WHO, 2017). In 2015, an estimated 47 million people were living with dementia worldwide this was projected to increase to 75 million by 2030 (WHO, 2017). In 2011 a diagnosis gap was

identified, it was estimated that approximately three quarters of people with dementia had not received a formal diagnosis (Prince et al 2011). The diagnosis gap is highest in low and middle income countries, however, in high income countries identification remains low, with 20-50% of cases identified (Prince et al 2011). The benefits of early diagnosis remain unclear (Prince et al 2011), however a formal diagnosis is required to access dementia specific support in many healthcare systems. Improving early diagnostic rates has become a priority in dementia policy worldwide, including the United Kingdom(UK) (Rosow et al 2011). Although determining accurate national diagnosis rates is challenging, UK studies have shown a steady increase in the number of people diagnosed since the National Dementia Strategy was introduced in 2009 (Donegan et al 2017, Mukadam et al 2014). The UK national dementia diagnosis rate is 68%, leaving just over 30% of people undiagnosed (NHS Digital, 2019).

Help seeking for a health problem can be described as "problem focused, planned behaviour involving an interpersonal interaction with a selected health care professional" (p286) with the intention of disclosing a problem in exchange for help (Cornally and McCarthy, 2011). The most common help seeking pathway in dementia would be for the person with symptoms to seek help from their primary care physician, usually with support of a family member or friend. Help seeking is a dynamic and complex process that can be influenced by many factors and understanding help seeking behaviour for specific conditions can help to identify and reduce delays to diagnosis and treatment (Scott and Walter, 2010). There has been considerable research into barriers to help seeking for a dementia diagnosis over the last 30 years, many of which have recommended improving knowledge and awareness amongst health professionals and the public to reduce delays and facilitate diagnosis. Mass media campaigns including World Alzheimer's Month (ADI, 2019a) and Dementia Action week in the UK (Alzheimer's Society, 2019), amongst others, have sought to increase public awareness. But despite some increase in diagnostic rates, there is limited evidence for successful interventions aimed at improving awareness and addressing factors such as GP knowledge associated with diagnosis in primary care settings in the UK (Mukadam et al 2015). In fact, increased public awareness has led to increased fear of diagnosis (Fox et al 2013).

There is no existing systematic review of the qualitative and quantitative research into barriers and facilitators to a dementia diagnosis from the perspective of persons living with dementia (PLWD) and their carers. Previous reviews have included health care professional and lay public views (Werner et al 2014), experiences post diagnosis (Werner et al 2014, Bunn et al., 2012), qualitative studies only (Bunn et al 2012, Rogers et al 2017, Perry-Young et al 2018) or focused on the influence of ethnicity (Mukadam et al 2011b).

The World Health Organisation (2017) set an ambitious target of a 50% diagnosis rate in a minimum of 50% of countries by 2025. This will be a challenge, not least due to the variation in the standards of dementia diagnosis data which is collected and monitored worldwide (OECD, 2018). But given that in some countries a word for dementia does not even exist, it will require significant investment in training, general awareness, and political will (ADI, 2018). In addition to improving diagnosis rates, research priorities in the UK include understanding what are "timely" and "quality" diagnoses of dementia and why people may voluntarily not seek a diagnosis (Pickett et al., 2018). By comprehensively synthesising the current literature from the perspective of PLWD and their carers, we aim to identify barriers and facilitators to a dementia diagnosis and potentially modifiable factors which could be the focus of future research and intervention.

2 Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Hong et al., 2018) and was registered in advance on PROSPERO (CRD42018092524).

2.1 Eligibility criteria

Qualitative, quantitative, and mixed methods primary research studies were included based on inclusion criteria (see Table 3.3 in Chapter 3).

2.2 Search Strategy

Nine databases were searched (MEDLINE Complete, CINAHL Complete, PsychARTICLES, PsychINFO, SocINDEX, Embase, Cochrane Central Register of Controlled Trials, BASE, Open Grey) between March-April 2018 by one author (MP). Additional searches to identify full publications of conference or poster abstracts were made and authors contacted for further information when necessary. A supplementary hand search of reference lists of final included articles and relevant systematic reviews was conducted. Subject headings and truncated keywords were used in the search in relation to three concepts: dementia, help seeking and timing of diagnosis with the concepts combined using "AND" for the final search. Full search terms and a full search for one database can be found in Table 3.4 in Chapter 3 and Appendix 3.

2.3 Study Selection and Data Extraction

Titles and abstracts of retrieved articles were subject to blind independent review by two authors (MP and either SB, JH or LA). Conflicts were resolved through discussion in the pair, involvement of a third author was not required. Full text of eligible articles were reviewed independently by two authors (MP and either SB, JH or LA) and any conflicts resolved through discussion. The data extraction form was piloted and reviewed following extraction of data from 10 articles. One author (MP) extracted data from all articles and two authors (JH, SB) checked 25% of these for accuracy. Care was taken to ensure studies were not double counted by cross checking author names and sample settings. Where multiple articles reported the same study, data were extracted onto the same form to ensure no omissions and to identify inconsistencies. Authors were contacted for additional information where necessary. Details of information extracted can be found in Appendix 4.

2.4 Quality Appraisal

Included articles were appraised using the Mixed Methods Appraisal Tool (MMAT)(Hong et al 2018). Designed for use in complex systematic reviews including qualitative, quantitative and mixed methods studies, MMAT consists of two screening questions and a set of questions related to the category of study (qualitative, or one of three types of quantitative study) with additional questions for mixed methods studies. All studies were independently assessed by two authors (MP and either SB, JH or LA) with disagreements resolved by discussion. No scoring was applied, and no studies were excluded on the basis of the appraisal. This ensured potentially valuable results in all studies were included in the final synthesis.

2.5 Data synthesis

A convergent qualitative synthesis approach was used to integrate findings (Pluye and Hong, 2014). Qualitative and quantitative data from individual and mixed methods studies were extracted and qualitative thematic synthesis used to transform quantitative data in qualitative data (Frantzen and Fetters, 2016). For example, in a study reporting 60% of participants agreed lack of knowledge was a barrier to help seeking, “lack of knowledge” was recorded as a qualitative barrier. An inductive thematic analysis of the data was then conducted by one author (MP) to produce integrated themes of qualitative, “qualitized” quantitative data or both (Lizarondo et al, 2017). Themes and supporting data were discussed between all authors to ensure consensus. First and second order constructs were analysed thematically to determine how barriers and facilitators interlinked and this is reported after the primary

synthesis of findings. Several studies focused on specific ethnic groups, so attention was paid during analysis to differences or similarities between ethnic groups and reported separately.

3 Results

Titles and abstracts of 7391 results were reviewed. Inter-rater agreement for inclusion was good (Kappa statistics: 0.73 - 0.82). Full text of 108 articles were reviewed, with 35 papers reporting 32 studies included (see Figure 4.1).

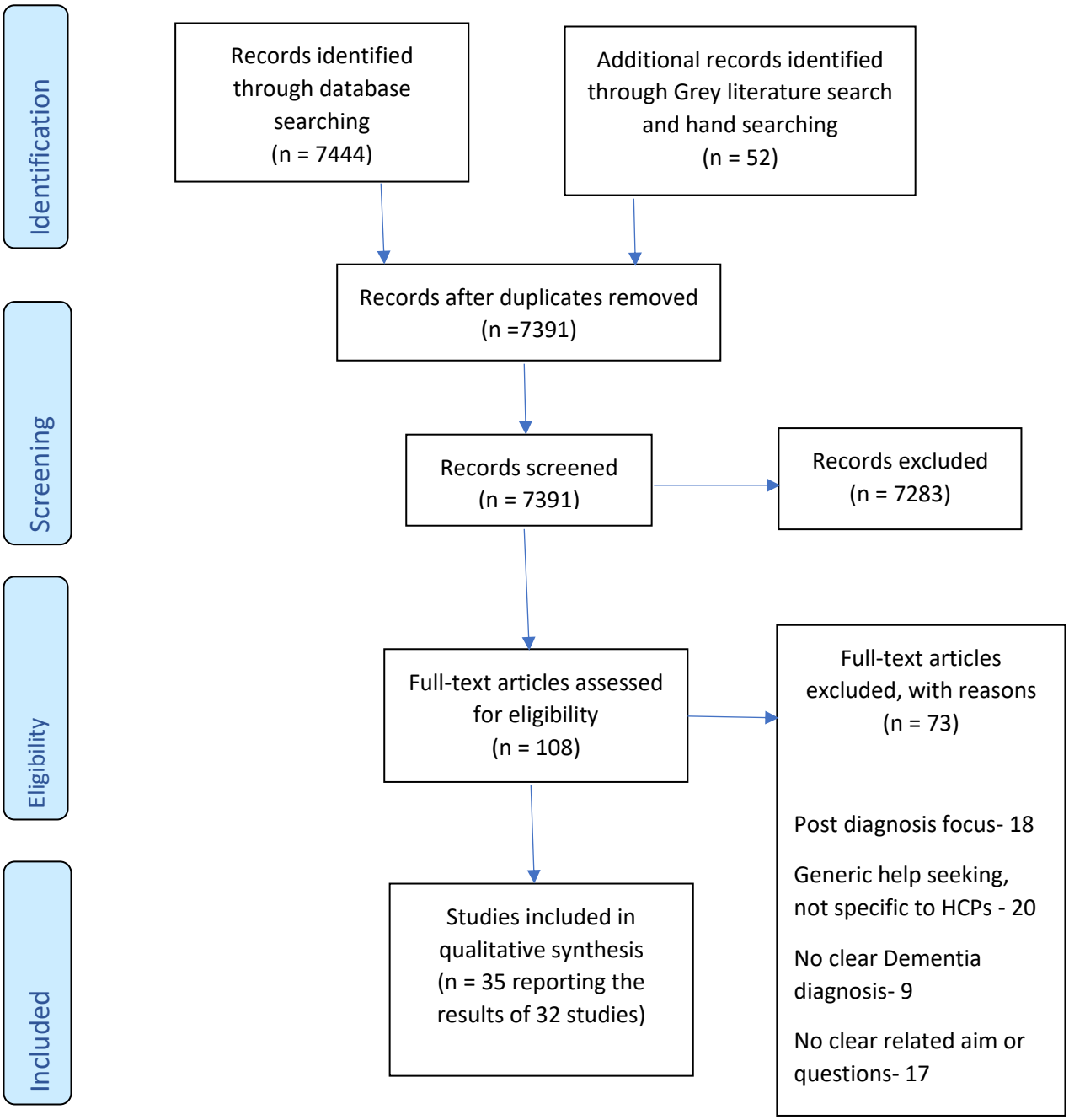


Figure 4.1 PRISMA Flow diagram

3.1 Study characteristics and quality appraisal

Of the included studies 19 were qualitative, 7 quantitative descriptive and 6 mixed methods. One mixed methods study reported qualitative results and quantitative results in separate papers (Wackerbarth and Johnson, 2002, Streams et al 2003). The characteristics of included studies are shown in Table 4.2. The perspective of carers were reported in 24 studies and the perspective of carers and PLWD in 8 studies (see Table 4.3), representing in total 4,618 carers and 158 PLWD. Full demographic characteristics of participants were not reported in all studies, but most carers were female and either spouses or adult children. Eleven studies sought the perspectives of specific ethnic groups. Two Hispanic and Latino communities within the United States of America (USA)(Ortiz and Fitten, 2000, Neary and Mahoney, 2005), four African American communities (Cloutterbuck and Mahoney 2003, Clark et al 2005, Hughes et al 2009, Jackson 2016), three Chinese communities in the USA (Zhan 2004), Canada (Koehn et al 2012) and China (Yan et al 2017), one of South Asian Canadians (McCleary et al 2012) and one UK study which purposively sampled South Asian, Black African or Caribbean, Asian, White and Chinese carers (Mukadam et al 2011a).

Study quality was variable, and the results of the appraisal can be found in Table 4.4. Qualitative studies were largely well reported. Quantitative descriptive studies lacked clarity of the representativeness of the sample population with possible high risk of non-response bias. Development and details of measurements used to collect data were limited but Clark et al (2005) used questions included in Knopman's (2000) study and the questions used in the Facing Dementia Survey (Rimmer et al 2005) were used in two subsequent studies (Tsolaki et al 2009, Jones et al 2010). No mixed methods study identified themselves as such and overall quality of individual qualitative and quantitative components and integration of results was poor.

Table 4.2 Characteristics of Studies				
Author/Year/ Country	**Aim of study**	**Sample**	**Design /Data collection**	**Key findings**
Chenoweth & Spencer (1986) US	To explore the experiences of families from the time of the earliest recognition of symptoms of dementia throughout the course of the illness	289 family members (289 survey, 13 follow up interview) 76.8% female 50% between 50-70 yrs. 99%White 91.7% reported diagnosis of Alzheimer's Disease (AD), others not reported	Mixed methods – mail survey with open and closed questions and telephone interviews	Barriers: refusal or resistance of the person with symptoms, difficulty talking to Dr Facilitators: symptoms accumulated and could no longer be ignored.
Connell & Gallant (1996) US	To examine attitudes of spouse caregivers about the process of obtaining a diagnosis of a dementing illness	233 carers 53% female Mean age 68yrs 91% White AD 54%, Unspecified cognitive disorder 21%, Huntington's disease 8%, Parkinson's disease with dementia 7%, Mixed cognitive disorder 5%, Multi-infarct dementia 3%, Progressive supranuclear palsy 2%	Mixed methods – mail survey with closed and open questions	Barriers: spouse not willing to be tested, family not agreeing it was important, belief that there is no cure, symptoms part of normal ageing.
Boise et al (1999) US	To determine time periods between the initial recognition by family members of symptoms of memory loss and seeking medical consultation and factors attributed to a delay in diagnosis	53 carers/ family members attended focus groups 191 carers responded to survey Focus groups: 84% primary carer, 67% female, mean age 54yrs Focus groups – diagnosis confirmed in medical records Survey – AD 67%, Other dementias 13% No demographic characteristics from survey respondents	Mixed methods – focus groups and mail survey	Barriers: carer lack of responsiveness to symptoms, not being aware, emotional difficulty of acknowledging a problem, barriers related to the PLWD, family conflict. Facilitators: a trigger event or recognition from others.

Knopman et al (2000) US	Description of factors associated with delay in diagnosis of Alzheimer's disease	1480 carers 52.4% female Mean age 58yrs 88% White 100% AD diagnosis	Quantitative - mail survey	Barriers: unsure of severity, normal ageing, difficult to raise the issue with the patient, patient became angry or refused to see doctor, could not face the possibility of AD. Facilitators: changes in behaviour, personality or disorientation
Ortiz & Fitten (2000) US	To explore perceived barriers to healthcare access in cognitively impaired older Hispanic patients	65 carers. 58% female Mean age 68yrs All Hispanic 68% diagnosed as having a dementia syndrome, others not dementia and results reported separately	Quantitative – structured interview using the Barriers to Healthcare Access Survey	Barriers: personal beliefs e.g. not trusting doctors or health services, believing they were too old for help, not needing help and not believing there is a problem.
Wackerbarth & Johnson (2002) Streams, Wackerbarth & Maxwell (2003) US	To identify the benefits and barriers perceived by family caregivers of persons who have been through a diagnostic assessment for dementia symptoms	520 carers 68% female Mean age 61.5yrs Diagnosis reported for 348 participants: AD 72%, Vascular causes of dementia 3%, Other dementia 13%, Other condition e.g. Parkinson's, Picks disease 6%, Short term memory loss 3%, Not dementia or reversible cause e.g. vitamin deficiency, depression 3%	Mixed methods – Survey with closed and open questions	Barriers: hard time accepting the decline, part of normal ageing, worried how diagnosis would impact my life, being forced to take away driving, worried about family members reaction Facilitators: Patient changes, recommendations from others and disruptive events.
Cloutterbuck & Mahoney (2003) US	To explore the perceptions and experiences of African American caregivers on their journey toward a	7 carers 71.4%female Aged 53-71yrs	Qualitative – focus group	Barriers: knowledge deficit, normalising symptoms and attributing them to ageing, respect for the PLWD.

	diagnosis of dementia for their loved ones	All African American		Facilitators: a crisis, serendipitous informal networking.
Teel and Carson (2003) US	To describe the experience of families in seeking diagnosis and treatment for loved one with dementia	14 carers 64% female Average age 62yrs (range 45-83) 100% White	Qualitative – semi structured interviews	Barriers: uncertainty about early symptoms Facilitators: progression of symptoms
Zhan (2004) US	To examine the experiences of Chinese American Caregivers who provide care for family members with AD and factors that hinder or facilitate obtaining an AD diagnosis	4 carers 75% female Aged 36 – 62yrs All Chinese American	Qualitative - Semi structured interviews	Barriers: Stigmatisation, lack of knowledge, language barriers Facilitators: other relative had dementia
Clark et al (2005) US	To identify early patterns of care for AD in a cohort of African American patients and their caregivers presenting at an inner-city clinic and a suburban memory assessment clinic	79 carers;46 from inner city clinic, 33 from suburban clinic Inner city clinic: 82.6% female, mean age 53.3yrs Suburban clinic: 72.7% female, mean age 55.2yrs All African American All diagnosed with probable AD	Quantitative – structured interview	Barriers: thought changes were normal ageing, unsure how severe the problem was, difficult to discuss with patient, difficult to face the possibility of dementia, patient became angry or refused to see doctor.
Krull (2005) US	To explore the process through which familial caregivers decide to seek out a formal diagnosis of Alzheimer's disease in their loved ones	13 carers 61.5%female All White	Qualitative, interactionist framework – semi-structured interviews	Barriers: normalisation of first signs or attribution to other causes e.g. stress, trauma, ageing. Facilitators: A pivotal event, support of outsiders, family history of dementia

Neary & Mahoney (2005) US	To explore the experience of dementia caregiving in an ethnically diverse sample of Latino caregivers	11 carers 81.8% female Average age 50yrs All Latino – Colombian, Puerto Rican, Argentinian, Guatemalan, Cuban, Dominican	Qualitative - Semi structured interviews	Barriers: denial and a failure to recognise symptoms due to lack of knowledge about dementia. Facilitators: recognising a problem
Rimmer et al (2005) Bond et al (2005) Europe	To assess attitudes and behaviours towards Alzheimer's Disease in Europe	618 carers and 96 PLWD PLWD aged 50-94, average 74yrs Approx. 15 each from France, Germany, Italy, Poland, Spain & UK Carers approx. 100 each from France, Germany, Italy, Poland, Spain & UK	Mixed methods – Carers Quantitative interview survey, PLWD qualitative interviews	Barriers: lack of awareness of symptoms, failure to recognise severity of symptoms, belief symptoms were those of other medical conditions or normal ageing, denial that a loved one could have AD Facilitators: Recognition of cognitive and behavioural changes PLWD did not comment on barriers or facilitators to diagnosis but expressed strong feelings of stigma towards their diagnosis.
Eustace et al (2007) Ireland	To determine the frequency of unrecognised dementia in a group of community dwelling elderly and identify factors associated with dementia recognition	62 carers Diagnosed by psychiatrist: AD 64.5%, Vascular dementia 12.9%), Mixed type 11.3%, Lewy Body Dementia (LBD) 3.2%, NOS (not otherwise specified) 8.1%	Quantitative – structured interview	Barriers: felt it was normal ageing, felt it was not a problem, PLWD refused to attend, did not feel anything could be done, would show a lack of respect
Carpentier et al (2008) Canada	To analyse service use barriers using the social representation approach	52 carers 78.8% female Mean age 66yrs	Qualitative, Social representation approach - Semi structured interviews	Barriers: stigma, lack of support from network, resistance from PLWD Facilitators: support from network, pressure from friends, contacts within network

		55.6% French as dominant language; 33.3% English speaking; 11.1% mixed situation or neither French or English as mother tongue All diagnosed with AD		
Speechly et al (2008) Australia	To describe the steps taken and delays encountered in the pathway to dementia diagnosis	209 carers 75% female Mean age 65.5yrs AD 58%, Vascular dementia 9%, Combination of types 6%, Unknown 12%	Quantitative – mail survey	Barriers: attributing the problems to something else e.g. stress, ageing; covering up symptoms or compensating for the patient, the patient refused help, arranged practice support
Hughes et al (2009) US	To examine the experiences of African American caregivers seeking a formal diagnosis for a family member with chronic memory loss	17 carers 82.4%female Mean age 59.8yrs (42-80) All African American	Qualitative using the Health Belief Model – semi structured interviews	Barriers: Changes were attributed to normal ageing, resistance from family members Facilitators: support from other family members
Tsolaki et al (2009) Greece	To assess the attitudes and perceptions of physicians, caregivers and the general public towards Alzheimer's Disease in Greece	100 carers.	Quantitative – telephone survey	Barriers: not knowing the symptoms were signs of AD, not wanting to accept the idea their loved one might have AD and not realising the seriousness and severity of symptoms. Facilitators: Behavioural problems and depression led them to seek help.
Carpentier et al (2010) Canada	To analyse the initial period of Alzheimer's disease (the period that starts with the first manifestations of the	60 carers 71.1% female 80% born in Quebec	Qualitative, Life course perspective - interviews	Findings identified five pathways into the care trajectory each with various barriers and facilitators: Type 1 families past experiences; Type 2 watershed events; Type 3 organisational effects; Type 4 complex

	illness and ends with the diagnosis).			trajectories with gentle negotiations and Type 5 complex trajectories with difficult negotiations.
Jones et al (2010) Europe	To update current knowledge on the attitudes and behaviours towards Alzheimer's Disease in Europe	250 carers 50 from each of UK, France, Germany, Italy and Spain	Quantitative – online questionnaire	Barriers: waiting until symptoms were no longer temporary, part of normal ageing, patient resistance to the consultation, symptoms of other medical conditions, denial that a loved one could have AD.
Leung et al (2011) Canada	To retrospectively explore the experiences of Anglo-Canadians with dementia and their carers regarding the sequence of symptoms and events that preceded the diagnosis	6 PLWD and 7 carers PLWD: 33.3% female, Aged from 50's to 70's Carers: 71.4%female, Aged from 30's to 70's All Anglo-Canadian AD 66.6%, Mixed Dementia 16.7%, Memory Problems 16.7%	Qualitative/ Phenomenology - Semi-structured interviews	Barriers: denial and attribution of symptoms to other causes. Facilitators: Carers encouraged the PLWD to seek help in the light of worsening and accumulating problems and confirmation from others.
Manthorpe et al (2011) UK	To understand the experiences, expectations and service needs of the person who is becoming the person with dementia from the perspectives of the older person and their supporter or carer	27 PLWD & 26 carers PLWD: 51.9% female, 88.8% over 65yrs, 96.3% White British, 3.7%South Asian Carers: 76.9% female, 50% over 65yrs, 96.3% White British, 3.7%South Asian 21 participants received dementia diagnosis during study, 6 waiting to receive diagnosis or had Mild Cognitive Impairment	Qualitative – interview with topic guide	Barriers: denied the problems, attributed them to ageing or did not see them as a problem. Facilitators: Confirmation and support from others and sometimes family pressure, knowledge of dementia from relatives that worked in healthcare or family history of dementia.
Mukadam et al (2011) UK	Explore the effect of culture and ethnicity on beliefs and attitudes of	18 carers 72.2%female Aged 27-85yrs, mean 57yrs	Qualitative – semi-structured interviews	Barriers: delaying until symptoms were unmanageable, attribution of symptoms to other causes, delays due to PLWD, different cultural

	carers to help-seeking for dementia symptoms	22.2%White UK, 27.8%South Asian, 27.8%Black African or Caribbean, 5.5% White Irish, 5.5%White other, 5.5%Asian other, 5.5%Chinese		expectations, delays due to family and because the patient was already seeing a doctor. Facilitators: worsening symptoms, safety concerns, other people noticing problems and practical problems.
Van Vliet et al (2011) Netherlands	To investigate the barriers to obtaining a diagnosis for caregivers of people with early onset dementia	92 carers. Carers: 52.2%female; Mean age: 59.3yrs AD 68%, Fronto-temporal lobe dementia 17%, Vascular (VaD) or mixed AD/VaD 10%, Other cause 5%	Qualitative, grounded theory – semi-structured interviews	Barriers: attributed symptoms to ageing and other causes, PLWD denied or covered up problems. Facilitators: symptoms became more pronounced, a significant limitation in functioning, a key incident, confirmation of others.
Chrisp et al (2012a) Chrisp et al (2012b) UK	To identify factors at different points in the journey that delay and facilitate first contact with an HCP.	20 carers 65%female All White British	Qualitative - interviews	Barriers: fears of resistance from the PLWD, co-morbidity, carer problems and adoption of carer role, denial, family conflict Facilitators: professionals noticing symptoms, crises and support from others
Koehn et al (2012) Canada	To study the pathway to a diagnosis of dementia as experienced by ten dyads of people with Chinese origin	10 PLWD and 11 carers PLWD: 20% female, Aged 72-86 Carers: 81.9% female 81.8%, Aged 59-81yrs All of Chinese origin All diagnosed with Alzheimer's disease and related dementias	Qualitative, critical constructionist and intersectionality lens – semi structured interviews	Barriers: Caregivers and PLWD normalised symptoms and attributed them to other causes, Facilitators: accumulation of changes or a crisis precluded the decision to seek care with family support.

McCleary et al (2012) Canada	To explore experiences of South Asian Canadian persons with dementia and their family carers in the time prior to a diagnosis of dementia	6 PLWD and 8 carers PLWD: 66.7% female, average age 80yrs (74-84) 3 born in India, 3 Sri Lanka, Carers: 63%female, all first-generation Canadians born in India or Sri Lanka	Qualitative – semi-structured interviews	Barriers: normalised early symptoms and attributed them to other causes Facilitators: Key incidents, recommendations from others, family support
Bunn et al (2013) UK	To test and contextualise the findings of a systematic review of qualitative studies looking at patient and carer experiences of diagnosis and treatment of dementia	3 PLWD and 12 carers PLWD: 33.3%female Carers: 58.3%female	Qualitative – focus groups and one to one interview	Barriers: stigma, normalisation of symptoms and lack of awareness of signs and symptoms. Facilitators: gradual awareness that something was wrong, recognition by others or a trigger event.
Garcia et al (2013) Canada	To describe the experiences associated with the pathway to dementia diagnosis among francophone Canadians	7 PLWD & carer dyads PLWD: 57.1% female, Aged 64 – 84yrs, 6 born in Quebec/Ontario, 1 immigrated from France 35yrs ago Carers: 71.4% female, Aged mid-forties – late eighties All diagnosed with either Alzheimer's disease or Vascular Dementia	Qualitative - interviews	Barriers: timely identification of symptoms, waiting for family members to come to terms with the potential diagnosis, fear of the PLWD's reaction and other health problems. Facilitators: accumulation of symptoms, hospitalisations or issues with hygiene, finance or safety.
Jackson (2016) US	To identify the barriers to accurate and early diagnosis of Alzheimer's Disease among African Americans from the perspective of family caregivers	8 carers 75% female Aged 41-84yrs All African American	Qualitative, grounded theory using the health belief model and attribution theory as a theoretical framework – Semi-	Barriers: uncertain about cause, attributing changes to personality or psychological conditions, denial, feeling that nothing could be done. Facilitators: recognised the changes were becoming severe

			structured interviews	
Feldman et al 2017 UK	To examine family carers accounts of first onset and symptom attribution when they first became concerned about their relative's early signs of dementia	84 carers 75%female, Average age 66yrs (36-88) 87% White UK, 7% White other, 2% Black Caribbean/Black other, 4% Indian AD 35%, Dementia 17%, Vascular dementia 12%, Mixed dementia 11%, LBD 5%, Picks Disease 2% Carer uncertain 19%	Mixed methods - Semi-structured interviews with closed and open questions	Barriers: If carers thought ageing was responsible, they were significantly less likely to seek help and less likely to seek help if attributed to other causes. Facilitators: If the carer thought dementia was the cause of symptoms, they were six times more likely to seek help.
Yan et al 2017 China	To understand the experiences of people with dementia and their caregivers in engaging in dementia diagnosis	3 PLWD and 20 carers PLWD: 55.6% female; Mean age 84yrs Carers: 80% female; Mean age 58yrs	Qualitative/ Gadamer's Hermeneutic principles and social ecological theory – Focus group and one to one interview	Barriers: stigma, perceptions, and beliefs of dementia in the community, fear, cost, normal ageing Facilitators: knowledge of dementia, recognition of symptoms, key incident

Table 4.3 Studies supporting barrier and facilitator themes

	Barriers										Facilitators		
Study	**Normalisation of symptoms**	**Lack of perceived need**	**Denial**	**Preserving autonomy**	**Lack of informal network support**	**Lack of knowledge**	**Problems accessing help**	**Stigma and fear**	**Unaware of changes**	**Carer difficulties**	**Recognising symptoms as a problem**	**Support from informal network**	**Prior knowledge and contacts**
Chenoweth & Spencer (1986)				■			■				■		
Connell & Gallant (1996)	■	■	■	■	■		■						
Boise et al (1999)	■		■	■	■	■	■	■	■	■	■		
Knopman et al (2000)	■	■	■	■	■						■		
Ortiz & Fitten (2000)	■			■			■	■					
Wackerbarth & Johnson (2002)/ Streams et al (2003)	■	■	■	■	■	■	■	■	■	■	■		■
Cloutterbuck & Mahoney (2003)	■			■		■					■	■	■
Teel and Carson (2003)						■					■		
Zhan (2004)						■	■	■					■
Neary & Mahoney (2005)	■		■			■					■		■
Rimmer et al (2005)/ Bond et al (2005)	■	■	■			■					■		
Krull (2005)	■										■		■
Clark et al (2005)	■	■	■	■							■		
Eustace et al (2007)	■	■		■			■				■		
Carpentier et al (2008)	■				■			■			■	■	■
Speechly et al (2008)	■	■	■	■									
Tsolaki et al (2009)		■	■			■					■		
Hughes et al (2009)	■		■		■						■	■	
Carpentier et al (2010)	■	■	■		■				■	■	■	■	
Jones et al (2010)	■	■	■	■							■		
Manthorpe et al (2011a)	✓	✓	■		■						✓	✓	✓
Leung et al (2011)	✓		✓								✓	■	
Van Vliet et al (2011)	■	■	■	■	■				■		■	■	
Mukadam et al (2011a)	■	■	■	■	■		■	■			■		
Chrisp et al (2012a)/(2012b)	■	■	■	■	■					■	■	■	
McCleary et al (2012)	✓	✓				■					■	■	
Koehn et al (2012)	✓										■	■	■
Garcia et al (2013)	■	■		■	■	✓					■	■	
Bunn et al (2013)	■					■		■			■		
Jackson (2016)	■	■	■	■	■				■	■	■	■	
Yan et al (2017)	■	■					✓	■			■		■
Feldman et al (2017)	■	■									■		■

Key: Shading represents carer supported themes; ✓ represents themes supported by person living with dementia

Table 4.4 Quality Appraisal of Studies

Mixed Method Assessment Tool criteria	**Qualitative**					**Quantitative descriptive**					**Mixed methods**				
Study	**Appropriate approach to answer question**	**Data collection methods adequate**	**Findings adequately derived from data**	**Interpretation substantiated by data**	**Coherence between data sources, collection, analysis interpretation**	**Sampling strategy relevant to answer question**	**Sample representative of target population**	**Measurements appropriate**	**Risk of nonresponse bias low**	**Statistical analysis appropriate**	**Adequate rationale for using mixed methods**	**Components effectively integrated**	**Results brought together in overall interpretation**	**Divergences and inconsistencies addressed**	**Components adhere to quality criteria of each tradition**
Chenoweth & Spencer (1986)	✓	✓	?	✓	✓	?	X	?	X	?	?	✓	✓	X	X
Connell & Gallant (1996)	✓	✓	✓	✓	✓	✓	?	✓	X	?	X	X	✓	✓	?
Boise et al (1999)	✓	✓	?	✓	✓	✓	?	✓	?	?	X	X	✓	✓	?
Knopman et al (2000)						✓	?	?	?	✓					
Ortiz & Fitten (2000)						✓	✓	✓	✓	?					
Wackerbarth & Johnson (2002) Streams et al (2003)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	N.B Qualitative & Quantitative aspects of study reported in separate papers				
Cloutterbuck & Mahoney (2003)	✓	✓	✓	✓	✓										
Teel and Carson (2003)	✓	✓	✓	✓	✓										
Zhan (2004)	✓	✓	?	✓	✓										
Neary & Mahoney (2005)	✓	✓	✓	✓	✓										

Rimmer et al (2005)/ Bond et al (2005)	?	?	X	✓	X	✓	?	?	?	?	X	X	X	?	X
Krull (2005)	✓	✓	✓	✓	✓										
Clark et al (2005)						✓	✓	✓	?	✓					
Eustace et al (2007)						✓	?	?	✓	✓					
Carpentier et al (2008)	✓	✓	✓	✓	✓										
Speechly et al (2008)						✓	?	?	X	✓					
Tsolaki et al (2009)						?	?	?	?	?					
Hughes et al (2009)	✓	✓	✓	✓	✓										
Carpentier et al (2010)	✓	✓	✓	✓	✓										
Jones et al (2010)						?	X	?	?	✓					
Manthorpe et al (2011)	✓	✓	✓	✓	✓										
Leung et al (2011)	✓	✓	✓	✓	✓										
Van Vliet et al (2011)	✓	✓	✓	✓	✓										
Mukadam et al (2011a)	✓	✓	?	✓	✓										
Chrisp et al (2012a)/ Chrisp et al (2012b)	✓	✓	✓	✓	✓										
McCleary et al (2012)	✓	✓	✓	✓	✓										
Koehn et al (2012)	✓	✓	✓	✓	✓										
Garcia et al (2013)	✓	✓	✓	✓	✓										
Bunn et al (2013)	✓	✓	✓	✓	✓										
Jackson (2016)	✓	✓	✓	✓	✓										
Yan et al (2017)	✓	✓	✓	✓	✓										
Feldman et al (2017)	✓	✓	X	✓	✓	✓	X	✓	X	✓	✓	X	X	✓	✓
Criteria for Quality appraisal: ✓= Yes, X = No, ? = can't tell															

3.2 Thematic synthesis

Themes were grouped into two categories: barriers and facilitators. Barrier themes were *denial, stigma & fear, lack of knowledge, normalisation of symptoms, preserving autonomy, lack of perceived need, unaware of changes, lack of informal network support, carer difficulties* and *problems accessing help*. Facilitator themes were *recognition of symptoms as a problem, prior knowledge & contacts,* and *support from informal network*. Qualitative and quantitative data supported all themes apart from one facilitator theme - *support from informal network*. This was supported by qualitative data only. Details of studies supporting each theme can be found in Table 4.3. In around half of the studies carers and PLWD reported more than one barrier or facilitator. Two barrier themes; *Problems accessing help* and *Preserving autonomy* were supported by studies over a 30-year period (1986- 2016/7). All other barrier themes were supported by studies over a 20-year period (1996/9 – 2016/7), except for *lack of knowledge* which was supported until 2013. One facilitator theme; *Recognising symptoms as a problem* was supported by studies over a 30-year period (1986-2017), the other two themes were supported by studies from a 15-year period (2002/3 – 2016/7).

4. Barriers

Denial

Denial related to participants feeling unable to face the possibility that signs and symptoms might be dementia. Eighteen studies across all countries supported this theme (see Table 4.3). Carers were most likely to report being in denial or unable to face the possibility of a dementia diagnosis (Carpentier et al 2010, Clark et al 2005, Wackerbarth and Johnson 2002, Rimmer et al 2005, Boise et al 1999, Tsolaki et al 2009, Knopman et al 2000, Jackson 2016, Jones et al 2010, Connell and Gallant 1996), sometimes despite PLWD trying to convince them otherwise (Manthorpe et al., 2011). This resulted in carers taking measures to keep PLWD safe or covering up and compensating for difficulties instead of seeking help (Neary 2005, Speechly et al 2008). When carers accepted there was a problem, denial by family or informal network members prevented or made help seeking more difficult (Hughes et al 2009, Carpentier et al 2010). In five studies the carer reported PLWD denied problems and covered up symptoms, delaying help seeking (Mukadam et al 2011a, van Vliet et al 2011, Chrisp et al 2012b, Wackerbarth and Johnson, 2002) and in some cases this persisted after help had been sought on their behalf (Manthorpe et al 2011) or caused an additional delay once a carer had decided to seek help (Eustace et al 2007, van Vliet et al 2011). In one study a PLWD reported ignoring their symptoms for a long time (Leung et al 2011).

Stigma and fear

Real or perceived negative attitudes toward dementia in society or fear of dementia diagnosis delayed the help seeking process in eight studies. Negative attitudes towards dementia and fear of how their family would be treated after diagnosis delayed help seeking for Chinese participants (Yan et al 2017, Zhan 2004). North American carers reported concerns that services would not accept a person diagnosed with dementia (Wackerbarth and Johnson, 2002), whilst Black UK carers cited stigma of mental illness and negative experiences of psychiatric services in their reluctance to seek help (Mukadam et al 2011a). Canadian carers delayed help seeking due to negative images of the disease or having witnessed others caring for someone with dementia (Carpentier et al 2008). Fear of diagnosis from PLWD delayed help seeking in four studies (Yan et al 2017, Boise et al 1999, Wackerbarth and Johnson 2002, Ortiz and Fitten, 2000). Poor prognosis, likening the diagnosis to cancer (Yan et al 2017), family history of Alzheimer's or worrying about reactions of others contributed to their fear and delayed help seeking (Boise et al 1999, Wackerbarth and Johnson, 2002). Stigma prevented discussion within informal networks (Carpentier et al 2008) and resulted in carers and PLWD colluding to hide symptoms (Bunn et al 2013).

Lack of knowledge

In eleven studies participants directly attributed delays in help seeking to a lack of knowledge. Participants reported lacking knowledge of early signs and symptoms (Cloutterbuck and Mahoney 2003, Bunn et al 2013), uncertainty about significance of symptoms (Garcia et al 2013, Teel and Carson 2003), lack of awareness that symptoms were signs of Alzheimer's disease (Rimmer et al 2005, Tsolaki et al 2009, Zhan, 2004) and lack of understanding about the nature of dementia (Neary 2005, Boise et al 1999, Wackerbarth and Johnson, 2002). This contributed to the difficulty some carers had differentiating between signs of normal ageing and dementia (Rimmer et al 2005, Neary and Mahoney 2005) .

Normalisation of symptoms

Participants normalised early symptoms attributing them to other factors such as ageing, physical and psychological health problems or stress and discounted them as warranting help seeking. Data from almost all studies supported this theme. Length of time spent normalising symptoms varied (Krull, 2005) but often occurred in the first year (Chrisp et al 2012b), when symptoms were mild and not interfering with daily tasks (Leung et al 2011). Carers in all the studies supporting this theme, except Carpentier et al (2010), commonly attributed symptoms

to normal ageing or as being normal to forget things (Koehn et al 2012, van Vliet et al 2011, Leung et al 2011). Others attributed symptoms to physical health problems or medication PLWD were taking (Wackerbarth and Johnson, 2002, Rimmer et al 2005, Mukadam et al 2011a, Carpentier et al 2008, Carpentier et al 2010, Feldman et al 2017, Jones et al 2010, van Vliet et al 2011, Leung et al 2011, Chrisp et al 2012a). Some attributed symptoms to the person's personality (Jackson 2016, McCleary et al 2012, Koehn et al 2012, Feldman et al 2017) or to psychological problems such as depression (Jackson 2016, van Vliet et al 2011, Leung et al 2011). Stressful life events in the past or present and being under stress, including work related stress for people with early onset dementia, were common attributions (Mukadam et al 2011a, Krull, 2005, Feldman et al 2017, Speechly et al 2008, van Vliet et al 2011, Leung et al 2011). Less common attributions made by carers were alcohol (Jackson 2016, Feldman et al 2017), cultural beliefs or perceptions such as "craziness"(Neary and Mahoney, 2005, Cloutterbuck and Mahoney 2003) and religious beliefs such as the work of a God (McCleary et al 2012). PLWD also normalised symptoms they were experiencing, as being normal to forget or make mistakes (McCleary et al 2012, Leung et al 2011, Manthorpe et al 2011), part of normal ageing (Koehn et al 2012, Leung et al 2011) or compared themselves favourably to others of similar age (Manthorpe et al 2011). Sometimes PLWD noticed problems earlier than their carers or reported symptoms undetected by the carer, resulting in differing interpretations of symptoms (Manthorpe et al 2011, Leung et al 2011).

Attributing cognitive decline to normal ageing was significantly related to a delay in help seeking in Feldman et al's (2017) UK study, prevalent across all ethnic groups and educational attainment level in Mukadam et al's (2011a) UK study and present when controlling for education, age, acculturation and ethnicity in Ortiz and Fitten's (2000) USA sample of Hispanic participants.

Preserving autonomy

Concerns a diagnosis would undermine the autonomy and independence of PLWD or carers respecting the wishes of PLWD delayed help seeking in sixteen studies. Carers respected PLWD when they refused or resisted seeking help and assessment (Boise et al 1999, Cloutterbuck and Mahoney 2003, Wackerbarth and Johnson 2002, Ortiz and Fitten 2000, Connell and Gallant 1996, Speechly et al 2008, Jones et al 2010, Clark et al 2005, Knopman et al 2000, Chenoweth and Spencer 1986, Eustace et al 2007, van Vliet et al 2011, Mukadam et al 2011a,Chrisp et al 2012b) or when met with angry responses to the suggestion of seeking help they did not pursue this further (Clark et al 2005, Knopman et al 2000, Chenoweth and Spencer, 1986).

Carers specifically expressed wanting to preserve and respect the autonomy or independence of PLWD (Boise et al 1999, Cloutterbuck and Mahoney 2003, Wackerbarth and Johnson 2002, Eustace et al 2007, Mukadam et al 2011a, Jackson 2016) and in some cases had difficulty discussing seeking help, worrying about how PLWD would react (Wackerbarth and Johnson 2002, Clark et al 2005, Knopman et al 2000, Mukadam et al 2011a, Chrisp et al 2012b, Garcia et al 2013, Jackson, 2016).

Lack of perceived need

Participants may have been aware that something was wrong but did not consider it sufficient a problem to seek a diagnosis in nineteen studies. Early changes were either not considered problematic (McCleary et al 2012, Ortiz and Fitten 2000,Eustace et al 2007, Manthorpe et al 2011, Mukadam et al 2011a) or not serious enough to warrant seeking help (Feldman et al 2017, Rimmer et al 2005, Tsolaki et al 2009, Jones et al 2010, Clark et al 2005, Knopman et al 2000, Garcia et al 2013, Jackson 2016). A common response was to provide practical help to support the person with daily activities or mitigate safety concerns (McCleary et al 2012, Speechly et al 2008, Chrisp et al 2012b, Jackson 2016, Koehn et al 2012). For other carers this was part of a 'watch and wait' process whilst deciding whether help was required (Jackson 2016). Feeling 'nothing could be done' as there is no cure or treatment for dementia resulted in delay when participants recognised that symptoms might be dementia (Wackerbarth and Johnson 2002, Yan et al 2017, Connell and Gallant 1996, Jackson, 2016). When carers felt a familial responsibility to care for PLWD, outside help was sometimes considered intrusive or that there was little to gain in seeking a diagnosis (Clark et al 2005, Mukadam et al 2011a).

Unaware of changes

In contrast, participants in five studies were not aware of any changes that may have required seeking help. The most common reason being PLWD living alone or at a distance and carers not seeing them regularly (Boise et al 1999, Carpentier et al 2010, Jackson 2016, Wackerbarth and Johnson 2002). For help seeking to occur someone living closer to the person needed to make the carer aware (Boise et al 1999) or they became aware after visiting their relative (Jackson 2016). Accessing help for PLWD was challenging at a distance, compounding the delay (Jackson 2016). Some carers felt they were too close to PLWD to notice changes (van Vliet et al 2011, Boise et al 1999) and were reliant on others to trigger awareness that something was wrong. Being unaware of changes was a barrier for carers in the USA, Canada and the Netherlands.

Lack of informal network support

Participants in thirteen studies looked to their informal networks for confirmation of symptoms and support to seek help but this was not always forthcoming. Help seeking was delayed when the informal network did not support the carer's desire to seek help (Carpentier et al 2008, Hughes et al 2009, Ortiz and Fitten 2000, Connell and Gallant 1996, Mukadam et al 2011a, Boise et al 1999, Wackerbarth and Johnson 2002, Jackson 2016, Carpentier et al 2010) or disagreed over the cause or seriousness of the problem (Chrisp et al 2012b, Garcia et al 2013, van Vliet et al 2011, Boise et al 1999, Wackerbarth and Johnson 2002). Even when convinced of a problem, carers were disinclined to seek help without support of others. Sometimes to prevent exacerbation of difficult family relationships they reverted to normalising symptoms or compromised and provided additional practical help to manage the problem (Carpentier et al 2008, 2010, Chrisp et al 2012b). Negotiations within the network could be hindered if family felt obligated to provide care rather than obtain outside help (Mukadam et al., 2011a), PLWD did not believe there was a problem (Chrisp et al 2012a) or the carer worked as a healthcare professional and others felt they lacked objectivity (Carpentier et al 2008). PLWD delayed help seeking if support from others to confirm their own suspicions was not forthcoming (Manthorpe et al 2011). Most studies refer to family members when seeking support, others refer to the informal network in general, making it difficult to determine whether size or make-up of the informal network influenced support provided. One carer reported that being an only child was a factor in her delay to seek help (Jackson 2016). Whereas in another study, a large network could hinder or support the carer and the relationship dynamics within the network appeared to be most influential (Carpentier et al 2010).

Carer difficulties

Carers delayed help seeking because of other life challenges or the perceived impact of a diagnosis on themselves in five studies. Carers were aware of a problem but delayed seeking help due to personal or family problems (Chrisp et al 2012b, Carpentier et al 2010). Others worried about the impact of a diagnosis, taking on a caring role or resented facing life changing decisions (Wackerbarth and Johnson, 2002) . Managing the PLWD's physical health problems or being overwhelmed by dementia related problems delayed seeking help (Chrisp et al 2012b, Boise et al 1999). The carers own fear of developing dementia caused delay in two studies (Jackson 2016, Wackerbarth and Johnson 2002). Carer difficulties were reported in studies from the USA, UK, Canada and the Netherlands.

Problems accessing help

Participants in nine studies were prevented from help seeking by practical barriers. Not knowing where to seek help was a barrier for carers in Ireland (Eustace et al 2007), the USA (Boise et al 1999) and one Asian carer in the UK (Mukadam et al 2011a). Assessment costs or lack of health insurance was reported as a barrier by USA carers (Connell and Gallant 1996, Boise et al 1999, Wackerbarth and Johnson 2002, Ortiz and Fitten, 2000) and PLWD in China (Yan et al 2017). Immigration issues, lack of transport or distance to clinics were barriers for Hispanic carers in the USA (Ortiz and Fitten, 2000). Language barriers were a problem for carers from ethnic minority groups (Zhan 2004, Ortiz and Fitten 2000). For carers in two studies from 1986 (Chenoweth and Spencer) and 1999 (Boise et al) difficultly articulating the problems they were seeing or discussing dementia symptoms with their doctor delayed seeking help. Similarly, being unable to discuss problems with doctors privately, rather than in the presence of the PLWD was reported by Boise et al (1999). Only two studies supporting this theme were conducted in the last decade, with small numbers of participants reporting such barriers.

5. Facilitators

Recognising symptoms as a problem

Once participants recognised that symptoms were a problem and could no longer be attributed to other factors, they sought help. Data from almost all studies supported this theme. Some participants recognised early symptoms as unusual behaviour and sought help quickly (Tsolaki et al 2009, Jones et al 2010, Feldman et al 2017, Neary and Mahoney, 2005, Manthorpe et al 2011, Chrisp et al 2012b). For others it could be years between first noticing symptoms and recognising them as a problem and seeking help. Gradual worsening of initial symptoms or an accumulation of problems, including behavioural or personality changes in addition to cognitive changes, led to recognition and seeking help (McCleary et al 2012, Knopman et al 2000, Clark et al 2005, Tsolaki et al 2009, Rimmer et al 2005, Krull 2005, Koehn et al 2012, Neary and Mahoney 2005, Teel and Carson 2003, Bunn et al 2013, Hughes et al 2009, Manthorpe et al 2011, Garcia et al 2013, van Vliet et al 2011, Leung et al 2011, Chrisp et al 2012b, Eustace et al 2007, Mukadam et al 2011a, Chenoweth and Spencer 1986, Streams et al 2003). For others it was realising the seriousness of symptoms or that they were no longer temporary (Jones et al 2010, Rimmer et al 2005, Jackson 2016). Some carers required a key incident to alert them to a problem. A hospital admission for physical problems or trauma, such as a fall, resulted in symptoms being recognised by health professionals (McCleary et al

2012, Koehn et al 2012, Bunn et al 2013, Garcia et al 2013, Chrisp et al 2012b, Jackson 2016, Yan et al 2017, Mukadam et al 2011a, Carpentier et al 2010, Boise et al 1999). PLWD becoming lost (McCleary et al 2012, Chrisp et al 2012b) or safety, legal or financial problems raised concern in others (Krull 2005, Garcia et al 2013, Streams et al 2003, Boise et al 1999). For some, a disruptive event such as the death of someone close to the PLWD, moving house or a holiday, revealed previously unrecognised problems (Neary and Mahoney 2005, Manthorpe et al 2011, van Vliet et al 2011, Streams et al 2003, Carpentier et al 2010, Boise et al., 1999). In most cases such events caused any previous normalisation of symptoms to fail. For some carers and PLWD, a friend or relative recognised the problem and confirmed their suspicions or alerted them to something they were unaware of (McCleary et al 2012, Feldman et al 2017, Krull 2005, Bunn et al 2013, Manthorpe et al 2011, van Vliet et al 2011, Chrisp et al 2012b, Mukadam et al 2011a, Leung et al 2011, Streams et al 2003, Cloutterbuck and Mahoney 2003, Carpentier et al 2008). Help seeking did not always happen immediately, sometimes requiring more than one person to suggest there was a problem before help was sought (Chrisp et al 2012b, McCleary et al 2012). Healthcare professionals seeing PLWD for other problems also recognised symptoms and initiated seeking help or suggested this to the carer (Chrisp et al 2012b, Mukadam et al 2011a, Streams et al 2003, Carpentier et al 2010). Progression of the disease and the characteristics and situation of the carer (e.g. the distance they lived from the person with dementia), influenced problem recognition (Krull 2005, Koehn et al 2012, Carpentier et al 2010).

Prior knowledge and contacts

Having contacts within health services or prior knowledge of dementia signs and symptoms resulted in prompt help seeking for participants in ten studies. Working in health services and a family history of dementia heightened awareness to early symptoms and prompted PLWD and carers to seek help (Manthorpe et al 2011, Krull 2005, Streams et al 2003, Zhan 2004, Neary et al 2005, Koehn et al 2012). Knowledge of the signs and symptoms of dementia from radio or television programmes, articles in magazines or from speakers at local community groups (Neary et al 2005, Koehn et al 2012, Streams et al 2003, Yan et al 2017, Manthorpe et al 2011) facilitated recognition of existing symptoms or new ones as they arose and prompted seeking help. In Feldman et al's (2017) study, the attribution of symptoms to dementia was significantly associated with seeking help earlier. Only two recent studies from the UK and China reported knowledge from the media as a facilitator to seeking help, the other three studies were 6-15 years old, suggesting the acquisition of knowledge may be more strongly related to individual carer actions than the success of recent public awareness campaigns.

Having a connection to a hospital, contacts within health services or recommendations of physicians to see, facilitated seeking help for some carers (Streams et al 2003, Carpentier et al 2008, Cloutterbuck and Mahoney 2003). One study reported that their contacts facilitated service access (Carpentier et al 2008), but it is not clear from the others whether these connections increased knowledge of dementia, helped to overcome practical barriers or provided informal network support.

Support from informal network

Support from the informal network was an important facilitator in seeking help in 12 studies. Carers sought confirmation and support from their informal network to make help seeking decisions once they recognised there was a problem (Hughes et al 2009, Carpentier et al 2010, Carpentier et al 2008, Cloutterbuck and Mahoney 2003, Chrisp et al 2012b), although which members of the network and the exact role they played was not always clear. For some carers the informal network provided legitimacy to seek help on the person's behalf (Chrisp et al 2012b) or other carers provided support and encouragement to seek help (Cloutterbuck and Mahoney, 2003). Family support was important, particularly for PLWD (Garcia et al 2013, Leung et al 2011, McCleary et al 2012, Jackson 2016, Manthorpe et al 2011, Koehn et al 2012, Carpentier et al 2010). French Canadian carers and PLWD were more inclined to share their situation with family than friends, as they helped in maintaining identity, grounding the PLWD and remembering who they were whilst awaiting diagnosis (Garcia et al 2013). For Anglo-Canadian PLWD, their family carer encouraged and assisted in seeking help, confirming concerns and helping to articulate this to physicians (Leung et al 2011). However family support was not always reported favourably with carers and PLWD in a UK study reporting seeking help resulted from the pressure of family members (Manthorpe et al 2011). Friends also put pressure on carers to seek help in a Canadian study (Carpentier et al 2008). Unsupportive informal networks could become supportive if they later recognised there was a problem or acquiesced and supported the carer if they were persistent about the need to seek help (Chrisp et al 2012b).

6. Connections between barriers and facilitators

It was common for carers and PLWD to report more than one barrier. Multiple barriers compounded the delay to diagnosis, often requiring more than one facilitator for help seeking to take place.

Fear and strong emotions associated with negative views of dementia were thought to contribute to denial in carers (Knopman et al 2000, Jones et al 2010, Tsolaki et al 2009, Rimmer et al 2005, Clark et al 2005). In turn a lack of knowledge contributed to this stigma and where support from the informal network was lacking, these negative views were reinforced. Denial, stigma and fear all led to the normalisation of symptoms (Leung et al 2011, Eustace et al 2007). Both normalisations and denial were seen as a way of preserving autonomy for the carer and PLWD when their sense of self was being threatened (Cloutterbuck and Mahoney 2003, Eustace et al 2007, Chrisp et al 2012b, van Vliet et al 2011) and as a way of self-preservation and coping when the carer was challenged by other life events or the potential impact of a diagnosis (Wackerbarth and Johnson 2002, Leung et al 2011, Krull 2005, Tsolaki et al 2009, Boise et al 1999). Normalisation of symptoms were compounded by a lack of knowledge (Neary and Mahoney 2005, Wackerbarth and Johnson 2002, Jackson 2016, Yan et al 2017, Hughes et al 2009, Koehn et al 2012) and led to a lack of perceived need (Eustace et al 2007). Normalisations could persist after help seeking, suggesting they were not the sole factor causing a delay (McCleary et al 2012). Lack of informal network support had the potential to compound or be compounded by all barriers. Stigma and fear, denial, a lack of knowledge or perceived need and normalisations within the informal network precluded the carer or PLWD getting the support they needed to seek help. In turn, lack of informal network support compounded these barriers in the carer or PLWD and increased the delay where a carer was unaware of changes or had other difficulties (Carpentier et al 2010). When problems were recognised by the carer or PLWD, help seeking did not necessarily follow and additional facilitators of support from the informal network or knowledge about dementia (Yan et al 2017) were often required to move from recognition of a problem to seeking help. Even where carers had professional knowledge of dementia, support from the family network was required to facilitate seeking help (Manthorpe et al 2011).

7. Role of ethnicity

Several studies focused on specific ethnic groups, however no barrier or facilitator was solely experienced by one ethnic group. Two larger programmes of work in the USA and Canada compared results across ethnic groups and found more similarities than differences in the barriers and facilitators experienced (Mahoney et al 2005, Koehn et al 2016). Differences related to the interpretation and experience of the barrier or facilitator rather than the barrier or facilitator itself. This was observed in other studies in this review. For example a lack of perceived need was a barrier across all ethnic groups but for Asian carers in one UK study this was due to PLWD not being culturally expected to undertake many household duties, so loss

of these skills was not perceived as a problem (Mukadam et al 2011a). Whereas Black African UK carers and African American carers reported a familial responsibility to provide care as their reason for not perceiving a need for help (Mukadam et al 2011a, Clark et al 2005). Participants in some studies related culture to reasons for delaying help seeking, for example normalisation of symptoms, but this was a barrier in almost all studies and across all ethnic groups.

There was variation in the extent to which some barriers or facilitators were reported between minority ethnic groups in this review. For example denial was reported by all ethnic groups apart from Chinese communities and in two USA studies using the same survey items, a greater proportion of African American carers reported denial as a factor (Clark et al 2005) than white carers (Knopman et al 2000). Stigma was a prominent barrier for Chinese participants in China and the USA, but not reported in a study of Chinese Canadians (Koehn et al 2012). Carers who normalised personality changes as intentional behaviour were from three different minority ethnic groups (Jackson 2016, Mukadam et al 2011a, McCleary et al 2012) and this normalisation was not reported in other studies. African American carers were the only carers from a minority ethnic group to report being unaware of changes and the only minority ethnic groups not reporting a lack of informal network support were those from Chinese and South Asian backgrounds, although Chinese participants reported a lack of family and community support post diagnosis (Zhan, 2004).

8. Discussion

This is the first review to systematically synthesise the qualitative and quantitative literature related to barriers and facilitators to seeking help for a diagnosis of dementia, from the perspective of PLWD and their carers. The barriers and facilitators identified rarely existed in isolation, demonstrating the complexity of seeking help for a diagnosis of dementia. Multiple barriers compounded the decision-making process for both carers and PLWD and more than one facilitator was often required to overcome these. Reviews of help seeking for a diverse range of health problems have acknowledged the complexity of the help seeking process (Rouhi et al 2019, Vestergaard Knudsen et al 2010, Planey et al 2019, Facione 1993), although none have been able to demonstrate the complex connections between barriers and facilitators that appear to exist in help seeking for a diagnosis of dementia. However, it is recognised that more qualitative research for help seeking for some health conditions is required to better understand contextual and interpersonal influences on help seeking.

More barriers than facilitators were identified reflecting the primary aim of studies. Despite spanning 30 years, there was consistency across time in the barriers reported. The presence of

barriers may be expected in low or middle income countries where dementia has only recently become a public health concern, such as China (Yan et al 2017). But the persistent presence of barriers in studies from the UK, USA, and Canada, particularly since the introduction of nationwide dementia policies with a focus on diagnosis and awareness, is harder to explain. These barriers are elements of a complex, interpersonal decision-making process for carers and PLWD long before contact with a health professional occurs.

Normalisation of symptoms was the greatest barrier identified in the review and was interconnected with other barriers. Previous reviews and studies on the pathway to a dementia diagnosis report on the complex, cyclical nature of the process, whereby people seek to make sense of the symptoms they are experiencing or witnessing (Rogers et al 2017, Perry-Young et al 2018, Robinson et al 1997, Keady and Nolan 1994, Wilson, 1989). This review adds to the complexity of the process by demonstrating that people are not only normalising whilst making sense of symptoms but using the normalisation process to protect the carer and preserve the autonomy of PLWD. Studies on awareness in early stage dementia suggest these are aspects of coping for the PLWD when their sense of self is being threatened by cognitive changes (Clare 2002), particularly in a society where the concept of the "person" and personhood are very much linked to intact cognitive functioning (Hughes 2011). A threat to identity and a sense of self was found to impact PLWD at all stages of the diagnostic process in another review (Bunn et al 2012) resulting in conflict for carers between protecting PLWD and promoting their independence (Perry-Young et al 2018, Boise et al 1999).

Denial, stigma and fear all contributed to normalisations and a lack of informal network support in this review and have been identified as barriers in other dementia help seeking reviews (Werner et al 2014, Bunn et al 2012, Mukadam et al 2011b). The stigma of a dementia diagnosis has a significant impact on the physical, psychological, and social wellbeing of PLWD and their carers and may be more widespread than studies in this review suggest. One study of Chinese USA carers had significant recruitment problems due to stigma within the Chinese community, and other studies have had similar difficulties recruiting PLWD and carers from different ethnic groups (Zhan 2004, Morhardt et al 2010). However public stigma towards dementia has been found to be high in diverse settings across Europe, the Americas and eastern countries (Mukadam and Livingston, 2012), so is not solely an issue to be addressed within specific ethnic groups. All PLWD and carers in the studies included in this review had eventually sought help for a diagnosis and it may be possible that stigma remains a strong barrier for those yet to seek help.

The significance of the informal network in supporting the carer and PLWD to seek help, particularly when faced with a potential loss of autonomy, cannot be underestimated and the findings of this review support this. Carer difficulties, even though supported by a small number of studies, were reported over a 20-year period and may reflect the difficulty in admitting to these barriers but represent an issue that remains relevant and possibly under reported. Even when convinced of the need to seek help, support of the informal network to legitimise the concerns of the carer or PLWD was required. Where too much risk or too little benefit is thought to come from seeking a diagnosis, the process will be delayed, resulting in help seeking at crisis point or remaining undiagnosed with a potential lack of appropriate support.

A smaller number of studies in this review reported problems accessing help or lack of knowledge as a barrier to seeking help. This could be explained by campaigns aimed at improving public awareness (for a range of examples see ADI, 2017) and work within healthcare services to improve diagnostic pathways in recent years. However, some carers and PLWD continued to attribute memory changes to normal ageing. This common misconception has been shown to exist even when knowledge of the symptoms of Alzheimer's disease is fairly good (Werner, 2003) and suggests greater awareness of the differences between age related cognitive changes and dementia is needed.

Diagnosis of dementia has been described as a key point of disempowerment for PLWD (Low et al 2018) and the barrier of preserving autonomy in this review would support that. The reduction of stigma and the empowerment of PLWD could be addressed through increased investment and focus on the creation of dementia friendly communities, as proposed in many national dementia plans, including the UK (Department of Health, 2015). The WHO and Alzheimer's Disease International see dementia friendly communities as an approach to creating societies where dementia is normalised and accepted as a disability (Lin and Lewis, 2015, WHO and ADI 2012). They have been described as a way for PLWD to be empowered and live their pre-diagnosis lives for as long as possible (Swaffer, 2014). As such they may be an important strategy to ensure PLWD and their informal networks feel confident that when they reach the point of seeking help they will be supported and understood rather than risk losing their identity or being stigmatised and isolated. For society to be truly "dementia friendly" PLWD need to be an integral part of the planning (Swaffer, 2014). National dementia plans for example in Canada, UK and Australia (all national dementia plans are available at ADI, 2019b) have actions related to dementia friendly communities, with a range of initiatives in place worldwide (for examples see ADI, 2019c) Future research to support the development of

dementia friendly communities could focus on how people interpret and experience barriers to help seeking. A more individualised approach is likely to be necessary in reducing barriers, particularly for harder to reach groups such as the oldest old and those who do not access services. As most studies focused primarily on barriers, a greater focus on facilitators would also be useful. Despite the inclusion of PLWD in more recent studies in this review, their perspective on the barriers and facilitators to seeking help is lacking. Although it is acknowledged that carers play a significant part in the help seeking process, future research needs to include a much stronger voice of PLWD, which in turn will contribute to reducing stigma.

9. Strengths and limitations of the review

This review is strengthened by the synthesis of mixed study types enabling a comprehensive review of the factors influencing help seeking for a diagnosis of dementia. Achieving meaningful integration of qualitative and quantitative data in a mixed studies review can be challenging but the authors have addressed this by following clear methods for a convergent qualitative synthesis resulting in a rigorous and transparent review process (Pluye and Hong, 2014, Frantzen and Fetters, 2016). Survey items and attitudinal statements in quantitative studies were generated by study authors, often following focus groups with carers, however, there remains the possibility that some important barriers or facilitators were omitted from structured surveys. The facilitator theme of *support from informal network* was only supported with qualitative data, however all other themes were supported by both qualitative and quantitative data suggesting that barriers and facilitators were captured comprehensively in all study types. All barriers or facilitators reported by participants in quantitative studies were coded and included, regardless of the proportion of participants reporting them. This was to ensure parity between barriers and facilitators reported by participants in larger quantitative samples and those reported in the smaller samples of qualitative studies. However, it is acknowledged this has the potential to overestimate the strength of some barriers or facilitators. Caution needs to be taken when interpreting findings related to the role of ethnicity. Sample sizes in studies of minority ethnic groups tended to be small and from specific geographic regions so may not be representative of people of the same ethnicity elsewhere. In addition, minority ethnic groups may differ in ways not related to ethnicity that influence their experience of barriers and facilitators (e.g. social class and level of education (Mukadam et al 2011b).The time lag in publishing studies and time from diagnosis to participation in studies could have resulted in some barriers appearing to be more relevant than they currently are, along with a possibility of recall bias. However, the consistent

reporting of the same barriers globally across mixed study types and over a 30-year period would suggest that the most important barriers and facilitators have been identified and that they remain relevant, even if for smaller proportions of the population than they had previously.

10. Conclusion

This review aimed to identify the barriers and facilitators to help seeking for a dementia diagnosis from the perspective of carers and PLWD and in doing so highlighted the complexity of the decision-making process. Studies from a 30-year period demonstrated that barriers to help seeking persist despite the increasing number of national dementia policies worldwide. Carers and PLWD experienced multiple barriers which often required more than one facilitator to seek help. Denial, stigma and fear and a desire to preserve the autonomy of PLWD contributed to the normalisation of symptoms, with the informal network playing a key role in the help seeking process. An increased focus on a wider societal approach including dementia friendly communities could be an important strategy in reducing stigma and fear and ensuring PLWD and their carers are supported and empowered in the pre-diagnosis period whilst deciding when to seek help.

4.1 Update to review March 2021

This section presents an overview of additional evidence from an updated search of the literature. The updated search results are presented here separately as the systematic review in this chapter has already been published. There have been seven new studies published since the searches in the original review were carried out, these studies met the inclusion criteria for the review, and would be eligible for inclusion. A summary of the relevant findings follows.

4.1.1 Updated Search

The three main databases in the original search (Medline, CINAHL and Psych Info) were searched in March 2021 using the original search terms and then limited to publications added from 2018 onwards. This resulted in a total of 3088 new papers once duplicates were removed. The eligibility criteria from the original search were applied and following a review of titles and abstracts, 14 full text articles were reviewed. Of these seven were eligible for inclusion in the review (Table 4.5).

4.1.2 Characteristics of the studies

Characteristics of the seven new studies can be found in Table 4.5. As in the original review, the seven new studies represented a range of countries, including Pakistan and Norway which had not been represented previously. Carers were the main participants in four of the studies, with PLWD included in three studies. All of the studies were qualitative, except one European cross-sectional survey. Data from this paper (Woods et al 2019) was 'qualitized' in the same way as quantitative data had been in the original review and analyzed along with the barriers and facilitators identified from the qualitative studies. The Mixed Methods Appraisal Tool (MMAT) (Hong et al 2018) was used to appraise the quality of the seven new studies, in accordance with the original review (Table 4.6). In keeping with the original review, the six qualitative studies were well reported. The quantitative descriptive study by Woods et al (2019) used an adapted version of a survey previously used with carers of people living with dementia, however the survey was largely delivered online, resulting in a high risk of non-response bias.

Table 4.5 Characteristics of additional studies following review update.

Author/Year/ Country	Aim of study or relevant question related to help seeking	Sample	Design /Data collection	Key findings
Rabanal et al (2018) UK	To explore the experiences and needs of younger people living with dementia	14 PLWD Aged 57-67yrs. All diagnosed before the age of 65	Qualitative – semi-structured interviews	Barriers: lack of awareness of young onset dementia, signs and symptoms seen in isolation and not always memory issues Facilitators: a point of crisis
Rasmussen et al (2019) Norway	To explore the family caregivers' experiences of the pre-diagnostic stage of FTD	16 caregivers 7 female, 1 not disclosed All diagnosed with fronto-temporal Dementia	Qualitative – semi-structured interviews	Barriers: changes attributed to ageing, stress, relationship problems, psychiatric or physical illnesses, denial of symptoms by person with symptoms, denial by carer, difficulty explaining symptoms to others
Woods et al (2019) Europe	To examine carers' experiences of the diagnostic process	1409 carers 227 from Scotland, 339 Italy, 268 Netherlands, 363 Finland, 212 Czech Republic 82.8% Female Median age 57yrs	Quantitative – cross sectional online/ paper survey	Barriers: Person with dementia refusing to be assessed, considered problems were due to old age, not aware of dementia, nothing can be done
Kokorelias et al (2020) Canada	To develop a conceptual framework of caregiving phases across the Alzheimer's Disease and caregiving trajectories	40 caregivers 50% female Mean age: spousal carers 75yrs, adult children carers 55yrs	Qualitative – telephone or video conference semi-structured interviews	Barriers: uncertainty about whether symptoms were normal ageing or possibly dementia

	and corresponding caregiver support needs			
Nguyen et al (2020) USA	To explore how Vietnamese American caregivers understand and provide care to family members with AD	20 caregivers 19 female All Vietnamese American All diagnosed with Alzheimer's disease	Qualitative – semi-structured interviews	Barriers: symptoms attributed to normal ageing or habit Facilitators: symptoms becoming progressively worse and disruptive
Willis et al (2020) UK/ Pakistan	To explore respondents' experiences with help-seeking, understandings of dementia, experiences with stigma and the role of religion among people with dementia in Pakistan	20 caregivers, 20 PLWD PLWD: 9 female; 1 aged 40-49, 1 aged 50-59, 6 aged 60-69, 8 aged 70-79, 3 aged 80-89, 1 aged 90-99	Qualitative – semi-structured interviews	Facilitators: PLWD or carer recognised something was not right, knowledge of medical concepts or had doctors in the family, already being treated for mental health problems, problems recognised by health professionals treating person for other health problems
Novek and Menec (2021) Canada	To critically examine the process of accessing and delivering a diagnosis of young onset dementia from the perspective of people living with young onset dementia, family members and providers	6 PLWD, 14 carers PLWD: 2 female; aged 57-66yrs Diagnosis: AD-4, LBD-1, unknown-1 Family members: 7 female; aged 20-76yrs Diagnosis of person cared for: AD-10, LBD-, FTD-1, unknown-2. All White Canadian	Qualitative – semi-structured interviews	Barriers: attributing signs to psychiatric illness, stress and lifestyle, denial Facilitators: recognition by a health professional, recognition by work colleagues, problems at work

Table 4.6 Quality appraisal of additional studies

Mixed Method Assessment Tool Criteria	Qualitative					Quantitative Descriptive				
Study	**Appropriate approach to answer question**	**Data collection methods adequate**	**Findings adequately derived from data**	**Interpretation substantiated by data**	**Coherence between data sources, collection, analysis interpretation**	**Sampling strategy relevant to answer question**	**Sample representative of target population**	**Measurements appropriate**	**Risk of nonresponse bias low**	**Statistical analysis appropriate**
Kokorelias et al (2020)	✓	✓	✓	✓	✓					
Willis et al (2020)	✓	✓	✓	✓	✓					
Rasmussen et al (2019)	✓	✓	✓	✓	✓					
Nguyen et al (2020)	✓	✓	✓	✓	✓					
Woods et al (2019)						✓	?	?	X	✓
Rabanal et al (2018)	✓	✓	✓	✓	✓					
Novek and Menec (2021)	✓	✓	✓	✓	✓					

Criteria for Quality Appraisal: ✓ = Yes, X = No, ? – can't tell

4.1.3 Relevant findings

The new studies had similar findings to the those included in the original review and reinforced the barrier and facilitator themes previously identified. A *lack of knowledge* often combined with *normalisation of symptoms* was common. Carers reported uncertainty about the cause of the symptoms they were witnessing (Kokorelias et al 2020, Woods et al 2019). This was particularly stark in carers of people with young onset dementia, where carers did not consider dementia to be a disease of younger people; consequently they attributed symptoms to psychological problems, stressful lifestyles or relationship problems (Rabanal et al 2018, Novek and Menec 2021, Rasmussen et al 2019). In common with studies in the original review many carers attributed early changes to normal ageing or the person's personality (Ngyuen et al 2020, Woods et al 2019, Kokorelias et al 2020). Some carers could move back and forth between attributing signs to normal ageing and considering the possibility of dementia, suggesting some knowledge of dementia (Kokorelias et al 2020).

Denial was also a theme in three studies. When the PLWD denied their symptoms, it made it difficult for the carer to seek help, but in hindsight carers also recognised they were in denial, as despite noticing changes, they did not want to acknowledge that these could be something serious (Rasmussen et al 2019, Woods et al 2019, Novek and Menec 2021).

The feeling that nothing could be done about the symptoms of dementia they were witnessing was expressed by carers in the large cross sectional study by Woods et al (2019) and is in keeping with studies in the original review in the theme, a *lack of perceived need*.

In the original review, in the theme of *problems accessing help*, carers in two studies from the 1980's and 1990's had expressed difficulty articulating the problems they were seeing to doctors and this had delayed help seeking. In one new study carers of people with fronto-temporal dementia also expressed the difficulty they had explaining symptoms to others, as it was hard to be precise about the changes they were witnessing and these could be misinterpreted by health care professionals as a problem within their relationship with the PLWD (Rasmussen et al 2019). This difficulty was also linked to the shame they felt about their loved one's behavioral problems (Rasmussen et al 2019).

Four of the new studies reported facilitators to seeking help and two of the three facilitator themes in the original review were supported by these new studies. *Recognition of symptoms as a problem* by the carer or PLWD was the most common facilitator, as symptoms became

progressively worse, behaviour more disruptive or there was a crisis (Rabanal et al 2018, Nguyen et al 2020, Willis et al 2020). In other studies, it took another person to recognise there was a problem including health professionals treating the person for other conditions and in the case of younger people with dementia, work colleagues (Willis et al 2020, Novek and Menec 2021). For carers and PLWD in Pakistan, *prior knowledge and contacts*, in the form of having some medical knowledge or having doctors in the family was a facilitator to seeking help (Willis et al 2020).

The two studies focused on people with young onset dementia and the one study related to people with fronto-temporal dementia (who had all started to experience symptoms in their 60's or younger) expand on the limited number of studies (n=1) with this specific focus in the original review (Rabanal et al 2018, Novek and Menec 2021, Rasmussen et al 2019). A lack of knowledge of young onset dementia led carers and PLWD to attribute their symptoms to a range of psychological, life and work-related factors often delaying help seeking for a considerable time period, with a significant emotional cost to the PLWD and their family members. As in the original review, recognition that symptoms were a problem often came late for carers in all of the new studies, at a point when the PLWD required considerable help with activities of daily living or after one or more safety concerns.

4.1.4 What the papers add to the original review and overall thesis

The findings of these seven new studies add to the findings of the original review. As the barriers and facilitators reported in these studies were often expressed as part of a wider exploration of carer and PLWD experiences, detail pertaining to the barriers and facilitators were lacking. No new themes emerged in the analysis of the findings of these studies but the findings do reinforce barriers and facilitators reported in the original review and the conclusion that carers often experience multiple barriers. The geographical spread of these new studies supports the conclusions of the original review that barriers continue to persist globally and further demonstrates the complexity of the help seeking process for a diagnosis of dementia. In the integrated findings of this thesis in chapter seven, the systematic review themes and data contributed to the overall integrated themes. The seven new studies presented here reinforce the integrated themes of 'Fear of the label of dementia', 'Alternative explanations' and 'The role of health care professionals', as carers and PLWD in these studies attributed symptoms to other causes, were sometimes in denial about the seriousness of the symptoms and health care professionals played a role in identifying symptoms and encouraging help seeking.

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Chapter 5: The bubble of normalisation: A qualitative study of carers of people with dementia who do not seek help for a diagnosis

This chapter presents the findings of the qualitative phase of the study. Previous studies of the pathway to a dementia diagnosis have focused on people who do eventually seek help and receive a diagnosis. Little is known about people who do not actively seek help. It is estimated that around a third of people living with dementia in the UK do not yet have a formal diagnosis (NHS Digital 2019). Consequently, understanding why people may not seek help is essential if interventions to improve diagnosis rates are to be successful and also to ensure that people who choose not to seek a diagnosis can receive the support they need. The qualitative phase of this study involved interviews with 12 carers of people who had not actively sought help for a diagnosis but received a dementia diagnosis during or following an acute hospital admission. The findings of this phase of the study were central to the integration of findings in Chapter Seven and abductive and retroductive reasoning in Chapter Eight. This chapter is in the format of an article for publication. The article has been submitted for publication and is currently under review. The article includes a brief introduction to the topic and methods, which have been covered in greater depth in Chapter One and Chapter Three. The findings of the qualitative analysis are presented followed by a discussion of the findings.

STATEMENT OF CO-AUTHORS of JOINT PUBLICATIONS

TO WHOM IT MAY CONCERN

Title of publication: The bubble of normalisation: A qualitative study of carers of people with dementia who do not seek help for a diagnosis

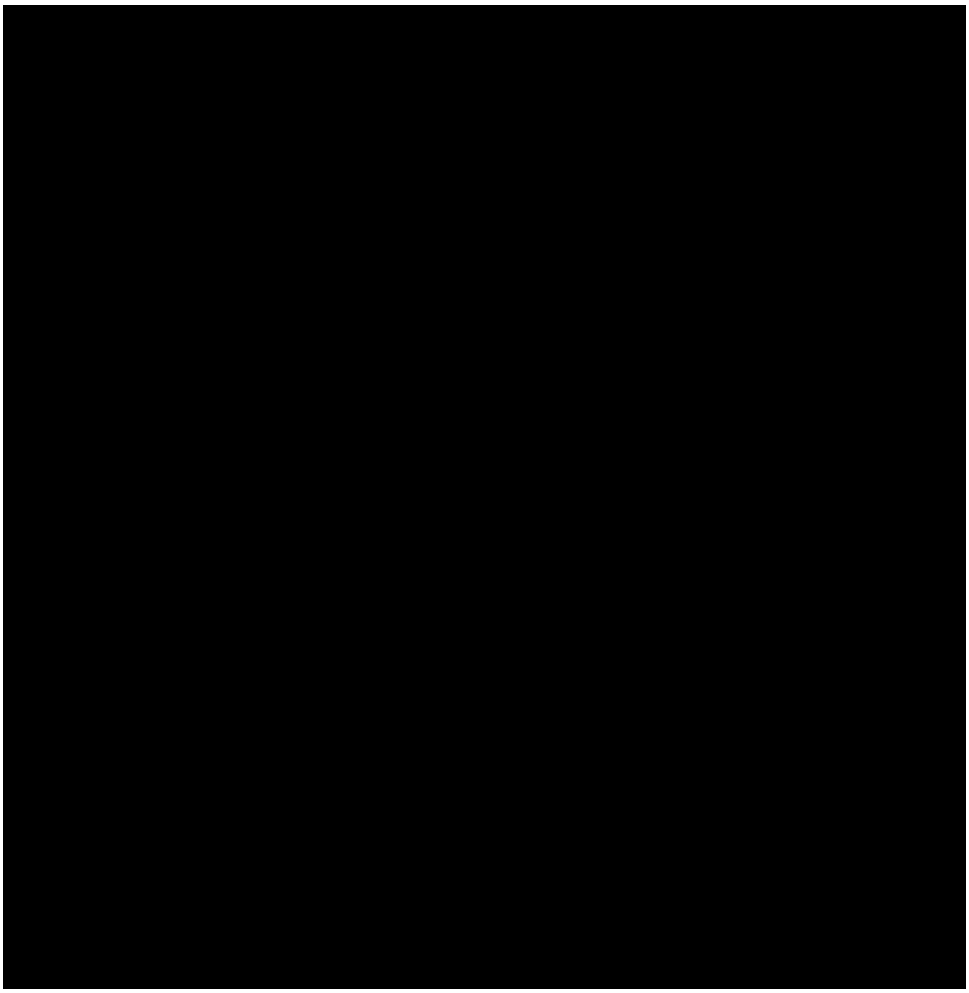
Name of candidate: Michelle Parker

Title of research thesis: We need to talk about dementia: Stigma and the role of the social network in preventing help seeking for a diagnosis of dementia

Name of first supervisor: Professor Leanne Aitken

We, the undersigned, co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.



Statement indicating the candidate's contribution to the publication

The candidate's contribution included:

- Gaining ethical approval
- Identification and preparation of participant identification centres
- Setting up the study on Join Dementia Research
- Recruitment of participants
- Data collection
- Transcription of five interviews
- Data analysis
- Data interpretation
- Writing and revision of the manuscript

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The bubble of normalisation: A qualitative study of carers of people with dementia who do not seek help for a diagnosis

Abstract

Objective: Improving dementia diagnosis rates are a key feature of dementia strategy and policy worldwide. This study aimed to understand the experiences of carers of a person living with dementia (PLWD) who did not actively seek help to gain a diagnosis. Semi-structured interviews were conducted with 12 informal carers of people diagnosed with dementia following acute hospital admission for a physical health problem, having not sought help previously. **Main Findings:** Carers created a 'bubble of normalisation' around themselves and the PLWD to reject the label of dementia and protect the PLWD from loss of independence, discrimination, and prejudice. Carers struggled to talk to the PLWD about dementia reinforcing denial and stigma. Post diagnosis carers felt unsupported and questioned the value of diagnosis. **Principal Conclusions**: Positive images of people living well with dementia and maintaining independence could promote greater openness to talk about dementia and lead to earlier help-seeking.

Keywords: Dementia, diagnosis, carer, stigma, normalisation, help-seeking

Introduction

Worldwide it is estimated that over 50 million people are living with dementia [1]. Yet it is estimated that up to 50% of people in high-income countries and 95% of people in low and middle-income countries have not received a formal diagnosis[2]. In 2017 the World Health Organisation set an ambitious target of 50% of people estimated to have dementia receiving a diagnosis in a minimum of 50% of countries by 2025[3]. Access to dementia diagnostic services and the standard of diagnostic data collected and monitored vary across the globe, resulting in difficulties in achieving and verifying diagnoses[4]. However, where dementia diagnostic services are widely available, a deeper understanding of why people do not seek help is needed.

Dementia strategies and policy advocate for a timely diagnosis, one made "at the right time for that person"(p1)[5] or when the person or their family "express concerns and have a need for advice, treatment or support"(p5)[2]. Despite this intention the term 'timely diagnosis' is often used to refer to a diagnosis made early in the disease process. In the absence of a cure or disease-modifying therapy, the proposed benefits to people with dementia and their carers of

a diagnosis early in the disease process include reduced anxiety and uncertainty about symptoms, ability to plan for future care and support and anticipate future problems[6]. However, evidence on benefits of diagnosis early in the disease process are lacking and based on expert opinion rather than research [2,6]. The pathway to a dementia diagnosis is recognised as being complex and involving an often-cyclical process of noticing, appraising and normalising symptoms until a point is reached at which this can no longer be maintained and help-seeking for a diagnosis begins[7-9]. For many people this can be a lengthy process, with studies suggesting an average of between four months and over three years between first noticing a problem and seeking help[10 11,12]. A recent review of barriers and facilitators to help-seeking for a dementia diagnosis from the perspective of carers and PLWD suggests multiple barriers often exist for the PLWD and carer, with more than one facilitator required to overcome these[13]. Barriers included denial, stigma and fear, a lack of knowledge about dementia, normalisation of symptoms, lack of informal network support, a desire to preserve autonomy of PLWD, a lack of perceived need for a diagnosis and the impact on carers [13]. The association between stigma and dementia is prevalent worldwide, but studies exploring the impact of stigma on PLWD and their carers are limited[1]. Importantly stigma is known to negatively impact social life, family relationships and experiences of health care resulting in lower levels of wellbeing and self-esteem amongst PLWD and concealment of diagnosis[1]. Fear of the reactions of others, negative images of dementia in the media, the lack of perceived benefit of a diagnosis and health professionals own stigmatising attitudes may also contribute to delayed help-seeking for a diagnosis[14].

Participants in studies exploring delays and barriers to diagnosis do eventually seek a diagnosis, and little is known about those who remain undiagnosed. The omission of voices from people in the latter group could represent a methodological bias in research, as it assumes that 'diagnosis is a crucial step' in the person's trajectory and does not consider those who do not want a diagnosis (p576)[15]. It is also possible that stigma plays a more significant role in the prevention of help seeking for dementia diagnosis than is currently supported with evidence. However, accessing a group of people in the community who are not seeking help, to understand their experiences, diagnosis wishes and support needs, is challenging.

In the UK around two thirds of people living with dementia have a formal diagnosis and initiatives in primary and secondary health care settings have been aimed at increasing formal diagnosis rates[16-18]. These included a case finding scheme introduced in England in 2012 to identify people with suspected dementia following emergency admission to an acute hospital

setting with a physical health problem[18]. The scheme provided an opportunity to identify undiagnosed dementia in people who had not sought help from a primary care physician.

Help seeking for a dementia diagnosis is most often initiated by a carer or close family member of the person with symptoms[8,9]. Carers or close family members of people identified as having undiagnosed dementia on admission to hospital present an opportunity to discuss the experiences and diagnosis wishes of a group of people who are not actively seeking help for a diagnosis. As part of a larger mixed methods exploration of what prevents help seeking for a dementia diagnosis, this qualitative study aimed to explore the experience of carers of people diagnosed with dementia during or following a hospital admission in order to identify factors that had prevented them from seeking help beforehand.

Methods

Methods are reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines[19]. Ethical approval for the study was granted by the NHS Research Ethics committee and Health Research Authority in England (IRAS 208826).

Study design

This study is placed within the overarching theory of critical realism. Critical realism provides a useful framework for studying healthcare decisions and has been used previously to explore delays in breast cancer diagnosis[20] and decision-making in home dialysis use[21]. It recognises that decisions, such as whether to seek help for a dementia diagnosis, are the result of a complex interplay of structure, "patterned arrangements in society such as norms and institutions" and agency, "capacity of an individual to act independently and to exercise choice" (p120)[22]. Structures have the power to enable or constrain the actions of agents, but through an 'internal conversation' agents have the power to determine if and how they are influenced by them [23].Participants had to be the main informal carer or next of kin of people whose diagnosis was initiated during or following an acute hospital admission for a physical health problem to be eligible for inclusion.

Procedures

Purposive sampling was used, and participants were initially recruited through the dementia teams of a large urban acute hospital in inner London following the diagnosis of a person with dementia. Only a small number of carers were recruited in the first 12 months (n=4) and in an effort to increase recruitment, a second acute hospital trust was accessed, and the study was registered on Join Dementia Research (JDR). Join Dementia Research is a National Institute for

Health Research (UK) service that allows people to register their interest in participating in dementia research and be matched to suitable studies. Participants were given information about the study either by nursing staff in the hospital dementia teams or were emailed information about the study by the researcher (MP) if identified as a carer for a PLWD on the JDR website. Interested participants were contacted by the researcher (MP) by telephone and email to discuss the study and arrange a face to face interview. The interviewer (MP) had not met any of the participants prior to interview. It is not known how many carers were given information by the hospital dementia teams, but 58 carers expressed an interest in the study from the JDR website. Of these only eight carers were eligible to participate. One carer identified by the hospital dementia team withdrew before their interview due to difficulties they were having arranging discharge for the PLWD. Sampling continued until data saturation was reached, i.e. when no new information was being heard [24]. Semi-structured interviews were used as the most appropriate method to gain an in-depth understanding of carers' experiences. A topic guide for the interview (Appendix 12) was developed, discussed, and reviewed with carers at a local Alzheimer's society memory café prior to ethical approval. Carers recruited into the study were interviewed once in a setting of their choice, with most interviews taking place in carers' homes. One carer was interviewed at the hospital, two at their workplace and two in public places. One carer was accompanied by another family member who did not participate in the interview. An explanation of the study and the opportunity to ask questions preceded the carer giving written informed consent to participate. Interviews were audio-recorded, and carers were offered the opportunity to receive a copy of the interview transcript. Interviews ranged from 24 – 73 mins in length.

Data analysis

Interview transcripts were analysed using an inductive, latent thematic analysis approach [25] . This approach is considered appropriate to use in critical realism as a method which can be used to both "reflect reality and to unpick or unravel the surface of reality"(p82)[25]. One author (MP) read and re-read the transcripts while listening to the audio recordings to familiarise herself with the data and then began coding transcripts. NVivo 12 Pro software [26] was used to facilitate coding. Codes were reviewed and collated into potential themes within three organisational categories – pre-diagnosis, diagnosis and post-diagnosis. Although an inductive approach to analysis was used, the author (MP) acknowledges her prior experience of working with carers and PLWD diagnosed during an acute hospital admission and how this may have influenced the coding and analysis process. A second author (SB) with a psychology

background reviewed a quarter of the transcripts and coding, and all themes were discussed and debated between the authors and reviewed and refined, as necessary.

Findings

Participant characteristics

The sample of 12 carers consisted of 10 adults caring for a parent (nine daughters and one son), one female friend carer and one female spouse carer. All carers lived in the greater London area. The people with dementia they cared for were diagnosed between 2010 – 2019 and were all aged in their 70's to their 90's at the time of diagnosis. Four people with dementia had died at the time of the interview. In the pre-diagnosis period, seven of the PLWD were living alone, three lived with the carer who was interviewed, and two lived with a spouse who was not the main carer interviewed.

Overview of Themes

Four themes represent the experience of carers from first awareness that something was wrong to post-diagnosis (Fig. 5.1). Two themes represent the pre-diagnosis period, each with two sub-themes. The first theme *Normalisation as a bubble* describes a 'semi-transparent barrier' that carers construct around themselves and the PLWD rather than seek help. Within the bubble the sub-themes *Explaining to normalise* and *To protect and preserve* describe the experience of carers as they navigate the increasing difficulties of the PLWD. The second theme *Missed Opportunities* with the sub-themes *Fear of talking about dementia* and C*ontact with health professionals* describe the missed opportunities there were to seek help in this period. The diagnosis experience for the carer is represented by the theme *Diagnosis-bursting the bubble*. The final theme of *What happens next*, with three sub-themes – *The doors close*, *Paying the price* and *Still not talking*, describe experiences of carers as they re-negotiate their lives after the diagnosis. Table 5.1 contains additional illustrative quotes from carers for all themes.

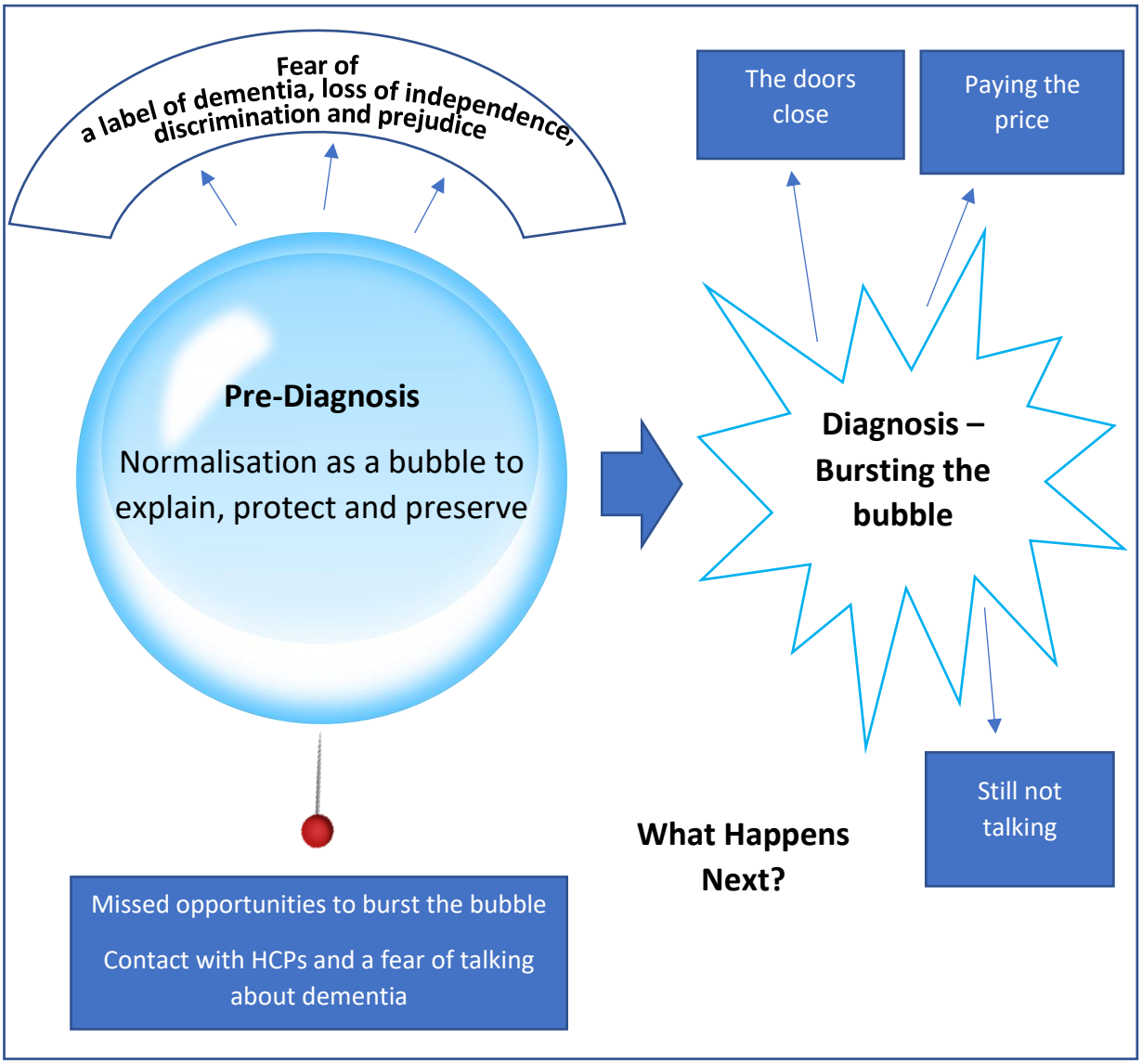

Figure 5.1: Visual representation of themes that illustrates how the bubble of normalisation is used by the carer to construct explanations that reject the label of dementia and protect the PLWD from a loss of independence, discrimination, and prejudice. Opportunities that threaten to burst the bubble are missed until the diagnosis bursts the bubble with consequences for the carer and PLWD.

Theme 1: Normalisation as a bubble

The first theme in the pre-diagnosis period describes how through a process of normalisation carers created a bubble around the PLWD, themselves and their lives. Within this bubble the sub-theme of *'Explaining to normalise'* describes how carers gradually realised that the changes they were witnessing in the PLWD were more than could be attributed to ageing or physical and mental health problems. They sought alternative explanations, which might

include dementia, but could reject this as a possibility. The second sub-theme – *'To protect and preserve'* describes how carers used the bubble of normalisation to protect themselves and the PLWD from a possible dementia diagnosis and to preserve the PLWD's independence.

Explaining to normalise

Carers sought to explain the changes they were seeing in the PLWD to normalise what was happening. Most carers could recognise, with hindsight, when the person they cared for started to have difficulty and reported memory problems as first symptoms, but also behavioural and personality changes or problems with self-care.

Many carers expressed an expectation that forgetfulness came with old age and that some cognitive decline would accompany increasing physical frailty. Most of the PLWD had additional physical or mental health problems, and while some carers attributed the changes they saw directly to these conditions, others felt that these masked cognitive changes:

> "She's always had mental issues. And it took a long time I think for me to distinguish between those and this new thing." (Carer 5)

However, for another carer attributing these early changes to ageing and the physical problems of the PLWD was easier to do, than accept that the changes might be dementia,

> "I thought it's a bit more, old age, she's forgetful, her diabetes. I never really, the dementia was on the edge, but I never really went there too much." (Carer 10)

At this point the carer feels there are legitimate alternatives they could attribute the changes to, so can resist the possibility of dementia. But as time went on this became more difficult for many carers. Although changes in personality could be attributed to ageing, for many there was a point of recognition that something was not right, and carers began looking for other explanations.

Although most carers were not living with the PLWD in the pre-diagnosis period, only one carer was unaware that the PLWD was having difficulties. But some carers struggled to explain the behavioural symptoms they saw from within their existing frame of knowledge, so constructed their own explanations as a way of normalising the behaviour, for example:

> "the names that she used to call me was like one of her sisters, and then again I thought maybe overnight you know when you're sleeping and thinking about things, maybe her sisters came into her mind." (Carer 6)

Over time, more than half of the carers considered that the symptoms they were witnessing might be dementia. A few carers had direct previous experience of dementia, either through work or members of their family. Others had enough awareness of dementia to consider it a possibility for the person they cared for and although some recognised it was a problem that required help, this was not enough to initiate the help seeking process. Others compared what they knew about dementia, to the changes they were witnessing, sometimes making downward social comparisons (comparisons to others considered to be less fortunate than oneself) to the relatives of friends who had dementia or images of dementia they had. Although these comparisons may have been misplaced, they helped some to conclude that dementia was not the problem.

> "a friend of mine, their mum is three days younger than my mum, …but she's repeats and repeats, …and it's all the time, but mums not like that." (Carer 3)

> "But he didn't have that before, so it's quite sudden…it wasn't sort of a gradual thing, which is what I've always thought, and from other people that I know" (Carer 4)

Such misplaced comparisons possibly resulted from a lack of knowledge, as memory problems are often the only symptoms referred to in awareness campaigns, but if the carer was looking to reject dementia as a possible explanation, such comparisons would help them to do this. Others sought advice from friends and family, which in most cases reinforced the attribution of problems to the ageing process.

> "so I spoke to friends and people but nobody I know has…experienced a relative with dementia. So it was very like, oh it's old age, this is what happens to people, and, you've got to expect it, she's getting on a bit." (Carer 10)

> "I did mention it to other people in the family like my sons, my nieces, nephews, to watch out for her…Some of them turned around and went, well… she is 90. I just think they think everyone of a certain age will forget things and so that's all it is, you know?" (Carer 11)

Although few carers spoke explicitly of denial, they relayed negative views of dementia. These

negative views often related to the progressive nature of the disease and the impact of it on the person.

> "…from my point of view, I was in denial…no illness is great, but dementia just robs you of so much" (Carer 10)

> "I've seen people with dementia and it's sad…because those that I had seen had no one to care for them. I'd seen people with dementia put in a home, negative things" (Carer 1)

> "a diagnosis of Alzheimer's or dementia is such a devastating thing" (Carer 8)

But they could also relate to the impact of the disease on the carer, such as whether the PLWD would recognise them, or to the stigmatising reactions of others.

> "Well, it's degenerative, isn't it? And you don't know where it's going to go. You don't know when the person will recognise you." (Carer 7)

> "I wouldn't like to be, if I get dementia in the future people just saying, oh yes she's got dementia. It's quite a label isn't it?" (Carer 5)

> "people are frightened by dementia… they're frightened cos it could happen to any of us and I think it's quite shocking to see… old age isn't pleasant for anyone is it… as you are older that you know it could happen to you and you will lose who you are as a person… its an awful thing…it makes you very vulnerable" (Carer 2)

These views seemed to influence their desire to normalise the changes they saw rather than formally seek help.

To protect and preserve

Carers used the bubble of normalisation to preserve and protect the way of life for the PLWD and themselves, but it also served to reinforce denial that dementia might be the cause of the problems.

For many carers the process of normalisation was a conscious one. They were aware that the PLWD was experiencing difficulties and used normalisation as a way of staving off fear about what the future might hold:

> "my head would think, oh my God, if it is dementia… she'd always say,…don't ever put me in a care home,…So in my head I knew that eventually if it came to that, that's where

we would be. So… my own mind was like, just let's just keep it in the day, she's all right for today, we'll deal with it as it gets, whatever happens we'll deal with it." (Carer 10)

Despite awareness that dementia may be the cause of her mother's problems, the carer tried to balance her mother's wishes for independence, with her own belief that having dementia inevitably meant institutionalisation. The fear of making such life changing decisions on behalf of her mother led her to deal with the problems day by day, to protect her mother from her own fear ("don't ever put me in a care home") and keep life as it is, for as long as she can. This was a conflict for many carers as they sought to balance the independence of the PLWD with their increasing need for support.

"She was quite an independent lady…she was quite proud as a person and a strong personality, she'd say Oh I'm fine, I like where I live and I don't need any help and… you do my jobs… I tried to put it to her someone would come in … to help you just get dressed and everything, it used to just upset her more than anything so I didn't really push her" (Carer 2)

"my mum was a very independent kind of lady, she could, she would only ask you to do something if she really, really couldn't do it" (Carer 6)

"you know in a way it's all about people's rights and you know we don't want to take too many rights away from someone who has dementia." (Carer 8)

"They showed me around [day centre] but she wouldn't have fitted in there at all … I could see the expression on her face…it was a bit going to be like a mother or a parent taking their child for the first time to school and then leaving them there and…I assured her…that's not the place for you" (Carer 1)

Carers managed this conflict by providing the care themselves if they could and put in place practical measures to support the person and mitigate safety concerns, for example moving the bed downstairs, moving to sheltered accommodation or moving to be closer to family members. Carers expressed a sense of duty to protect the person, supporting them practically to take "the fear out of it".

Another carer described constructing, "a semi-transparent barrier, you know one of the ones where you think if you just live day by day things will resolve, resolve themselves right". This

creates a vision of normalising as a 'bubble', in which the carer, the PLWD and their way of life are protected and preserved and one that only the diagnosis of dementia could burst.

There was a sense that a formal diagnosis or labelling of the problems as "dementia", somehow made them more real. Although many carers appeared aware of the progressive nature of the disease, by not seeking a diagnosis, they were delaying a process that would not begin until a diagnosis was made. This was particularly stark in one carer's experience, when as his mother received a diagnosis towards the end of her life, he expressed a sense of relief that she was, "not going to live through dementia", despite having had quite severe behavioural and psychological symptoms of dementia for a long time.

For another carer there was a fear that a label of dementia would mean her mother could no longer stay in the supported accommodation she lived in, and this carer actively resisted requests from staff at the accommodation to seek help for a dementia assessment. In discussing this the carer describes how,

> "you're fighting a lot of negative stereotypes about old people…and if you add the label of Alzheimer's on top of that… you really are up against an awful lot of prejudices" (Carer 5).

A diagnosis of dementia had the ability to add to the prejudices and discrimination that older people in society already faced. Suggesting that the process of normalising may be used not only to protect the person from a diagnosis which will change their life but also to protect them from the reactions of others and societal prejudices towards people with dementia.

The fear and reactions of others towards PLWD could make maintaining normalisations and protecting the person more difficult for the carer. One PLWD in sheltered accommodation encountered discrimination from other residents, as seen in the extract below,

> "people that had been her friends, they turned on her because they found it disturbing… they would get upset by it and they were going we can't cope because I'm old, I don't want this lady giving me her problems and it was awful because in a way she got bullied… it was also isolating her more." (Carer 2)

As other residents were urging the carer to seek help, the carer was torn between respecting the autonomy of the person, who had expressed she did not want any help from social services and protecting them from the discrimination of others.

Maintaining normalisation became increasingly difficult for carers over time, as PLWD needed increasing support with activities of daily living, had instances of getting lost, forgetting to take

medication, and burning saucepans. Despite the increasing burden, help seeking for a diagnosis was not an option carers considered, instead this was outweighed by their desire to protect the person and maintain the bubble of normalisation.

Theme 2: Missed Opportunities

The second theme in the pre-diagnosis period is 'Missed Opportunities'. The two sub themes - *'Fear of talking about dementia'* and *'Contact with health professionals'* represent missed opportunities to seek help for a diagnosis.

Fear of talking about dementia

Fear of talking about dementia prevented carers and people with dementia from discussing seeking help, thereby maintaining the bubble of normalisation. Only a small number of carers spoke to the PLWD about their concerns and in all cases their concerns were dismissed by the PLWD. Carers attributed this to the pride and independence of the person and to their personality:

> "she just [said], oh no, I'm all right, it's just old age. She wasn't worried about it." (Carer 10)

> "I did speak to her…I'd say no I'm worried you might need some help and everything, but she's always been independent so it's not something she wanted." (Carer 2)

> "[He] would never discuss whether he would be cremated or buried, for example. He just wouldn't talk about that sort of thing…So…it wasn't surprising that he didn't want to have a test because he just, he didn't like talking about things like that." (Carer 7)

In the final quote above, likening the discussion of dementia to the discussion of death, suggests fear. There was a belief that even having a test for dementia equated to talking about death, and the carer felt this fear was understandable, so the difficulties were not spoken of again and the bubble of normalisation was maintained.

Most carers did not discuss their concerns with the PLWD. In defending their decisions not to talk, carers again spoke of the independence and personality of the PLWD:

> "she's always been so fiercely independent…I don't think she'd have entertained it at all. Not at all. And she'd have probably been really, really angry with me for bringing it up." (Carer 11).

> "she's very protective of herself and very 'nobody knows me better than myself thank you very much'. And we could never have those discussions." (Carer 5)

But they also evoked fear of not wanting to damage the relationship they had with the PLWD, by making them angry or changing the relationship they always had. Such relationships, based on autonomy and respect, may have been valued by the carer over any benefit they perceived from suggesting seeking help.

By respecting what they thought the PLWD would want, the carer's own desire to maintain the status quo could be enabled. Very few PLWD expressed their concerns to carers in this study. But when they did, carers were dismissive and sought to reassure them that nothing was wrong, despite most having concerns that the person might have dementia.

> "I'd go, mum, it's all right, it happens to all of us, perhaps you're a bit tired or, you've got a lot on your mind and just try and put her mind at rest." (Carer 11)
> "I remember him once saying to me, something terrible has gone wrong with my brain…. But however much it might have gone on inside him, he didn't really manifest it like that and I tried to be, not to engage with it at all" (Carer 8)
>
> "he used to say, when he was getting, becoming a bit forgetful, but no more than anybody else really, oh I must have dementia, I must. I said dad, you don't have dementia" (Carer 4)

Two carers described how the PLWD had recorded their concerns in a diary, which the carer was not aware of until after the death or diagnosis of the person.

> "he used to keep a diary sometimes of events…the way he felt about things…and he said 'something's happened that's changed everything, I'll keep you up to date' in other words talking to the computer, I'll update it and there's no other entry." (Carer 8)
>
> "he was concerned about his health and keeping a log but wasn't necessarily sharing it with people" (Carer 9)

On reflection the carer above wished she had possessed, “the tools to talk to both of my parents and really get them to open up about the severity of their symptoms…I think it would have pushed me to do more of that diagnosis.” (Carer 9).

The opportunities to have a conversation that might lead to seeking help were missed, and for most carers the feelings and wishes of the PLWD were unknown. This unspoken truth served to reinforce a denial of the possibility of dementia and the bubble of normalisation.

Contact with health professionals

There were missed opportunities either for the carer to seek help when they encountered health care professionals (HCPs) or for an assessment and diagnosis to be initiated by HCPs. Many of the people with dementia were already seeing their General Practitioner (GP) regularly for other physical health problems, and in most cases, they were attending these appointments alone. Carers respected the person’s wish to attend alone and as such did not know whether the person had expressed concern about their problems to their GP or if their GP had expressed concern to them. Some carers felt it was likely that the person’s GP was aware of problems:

> “He was being seen by the GP fairly regularly for other things, because he’d had three hips and a knee and he’d had a heart valve and so he was being seen reasonably frequently…I’m sure the GP noticed differences. So, I think it would have been that the GP could have suggested a diagnosis.” (Carer 7)

> “because she was on warfarin, she was going to see a doctor every month. And they had not said anything about her mental condition. The only time I was allowed to take her to the GP was when she couldn’t walk…I did that for a couple of visits, but nobody suggested anything” (Carer 10)

> “I accompanied her, and the doctor refused to give her more. She was on low dose diazepam…A, because she’d been falling, B, because it was diazepam, C, because the doctor I think realised this wasn’t anxiety, this was dementia.” (Carer 5)

For the PLWD described above, their GP was clearly familiar with them, and there was an expectation from carers that the GP would have had concerns or made a diagnosis. As one carer expressed, “what would really have been useful, would have been the doctor [GP] to say to me, look, your mother’s got this, and for her to say it to my mother as well”.

Some carers might have welcomed a diagnosis if the GP had initiated it at this point. In this way the carer would have been absolved of making decisions to seek help against the wishes of the PLWD or have a difficult conversation with the person about their concerns. The GP would have assumed responsibility and taken it out of their hands.

In the same way physical problems could overshadow cognitive problems when carers first noticed changes, physical health problems continued to dominate carer's contact with health services. However, their contacts with primary and secondary care services were limited to managing individual problems, e.g. a urinary tract infection or a fall. Despite having their own concerns, carers did not use these opportunities to seek help, even when they were aware that the person had brief memory assessments in hospital. Some may not have realised that these were appropriate times to express their concerns, but for others, they were not yet ready to take the next step and pursue a diagnosis:

> "they did some sort of MRI or PET scan…they saw that there was a certain loss. But it didn't trigger anything in us because you know we were ignorant… but somehow there's a barrier beyond which none of us wants to go." (Carer 8)

This carer recognised that their lack of knowledge might be the contributing factor to not asking for more information about the scan results or seeing this as an opportunity to express their concerns. They also acknowledged that maybe they did not want to know and did not want to cross 'a barrier' that may lead to a dementia diagnosis. Making excuses for the PLWD's poor performance on memory tests was also easy, particularly when the PLWD's first language was not English,

> "a nurse came round, and gave her a dementia test… which she didn't pass, but only because she didn't understand… because she was speaking English." (Carer 1)

> "usually there was ten questions…I was wondering whether she didn't know or sometimes she was a bit stubborn, she didn't want to speak…I thought, I'm sure even if they asked me sometimes I will probably not remember" (Carer 6)

A few PLWD had been assessed by a memory clinic or community memory team at some point, although not diagnosed with dementia. Carers seemed uncertain as to the outcome of these assessments and sometimes dismissive of them,

> "the doctor referred us to the Memory Clinic…and he wasn't [diagnosed with dementia]. So… I don't know, I just think he was looking for a bit of sympathy" (Carer 4)

> "we went a couple of times to the memory clinic…They just talked to her and did a few tests…but nobody really said she had dementia." (Carer 10)

This may reflect the struggle carers had in discussing the outcomes of memory assessments with the PLWD and what these might mean for the future. It may also represent the carers own fears and a wish not to confront the possibility of a future in which their loved one has dementia.

For a few carers, their experience of contact with health care services was that of a "fragmented system" as the person moved between primary and secondary care services or between physical health, mental health and social services.

> "They just, I think they might have assumed that she'd already been diagnosed or she was about to be diagnosed or things were in hand". (Carer 5)

Carers recognised the missed opportunities to seek help with hindsight, but again there was an expectation that HCPs would have initiated this.

> "they can see the signs, so why don't the medical people tell me that they can see the signs, what are they frightened of telling you." (Carer 3).

This carer suggested that the stigma of dementia extended to HCPs and described it as,

> "it's almost like it's a taboo subject… do you think that people might think well you don't wanna know or something? You don't wanna know that your mums got dementia or you don't wanna know that your dad's got Alzheimer's" (Carer 3)

Stigma faced in clinical settings represented a real conflict in carers, who in their process of normalising had avoided talking about or seeking help for a diagnosis of dementia, but with hindsight wished HCPs had taken the opportunity to make a diagnosis.

When one carer attempted to seek help the system itself proved a barrier, with each service seemingly reluctant to be the one that initiated the diagnosis:

> "social services push you to the mental side, because she mentally needs to be assessed…but he [mental health worker] said no social services have to deal with it first…so they just both bashed her backwards and forwards, no-one was interested really" (Carer 2).

Contact with health care professionals seemed to be full of missed opportunities, not only for the carer to express their concerns but also for HCPs to acknowledge their concerns and ask the person and/or carer if they wanted an assessment for diagnosis. Carers appeared to expect HCPs to initiate the conversation and assessment, but at the same time HCPs might have expected carers or the PLWD to initiate the conversation if they had concerns or needed help.

Theme 3: Diagnosis - Bursting the bubble

For all carers a point came where their bubble of normalisation was burst, and a diagnosis of dementia was made. Most of the diagnoses took place in hospital with a small number happening in the community following discharge. A few carers played a role in initiating the assessment and diagnosis during or following the hospital admission. These carers used the admission as an opportunity to ask for symptoms to be investigated or knowing that investigations had taken place, asked for these to be followed up either whilst the PLWD was still in hospital or after discharge:

> "I kept saying that I'm really worried about her…then I saw the doctor as much as I could and then I think they said to me that there'd be someone [to assess PLWD]" (Carer 3)

> "a lovely consultant there…she did a brief capacity test on her because I mentioned it to her that I was concerned. And she got things wrong, so she said, oh, this is something we'll have to follow up while you're in here." (Carer 11)

> "I knew that they had done a scan. So, I asked if, could they look at it and tell me whether they thought that he did have dementia." (Carer 7)

For the carers above whose parent had either dismissed their concerns and refused to talk about what was happening, or where the carer had felt unable to discuss their own concerns, the admission to hospital and investigations that took place gave them a legitimacy they had not previously felt, to seek help on the PLWD's behalf.

The decision to assess and diagnose the person happened without the carer's involvement in some cases and sometimes without them being aware. The diagnosis was disclosed over the phone by a hospital psychiatrist or doctor from the memory clinic to some carers. For others it was in person, but some carers appeared quite vague as to who exactly had told them, either because of the passage of time or because it came amongst many conversations they had with doctors during the admission. One carer only became aware of the diagnosis from reading the PLWD's discharge notes.

Many carers suspected the person might have dementia but had explained and normalised what was happening over a significant period of time. However, on receiving the diagnosis they expressed a range of emotions. Some were relieved because "we needed to know what was the matter with her" and because "I believed it anyway, but it's always nice to have something confirmed". For others there was fear and disbelief:

> "So when he said quite categorically that she has Alzheimer's I was slightly shocked, defensive. But that labelling I think gets in the way also…that even if you know that this is the right diagnosis you're going to keep that to yourself in certain contexts." (Carer 5)

> "I was really frightened…everything they were saying I wasn't accepting it because I wanted my mum to be the mum I knew." (Carer 6).

The naming of the problem, the label of dementia, provoked an emotional response for these carers. In the earlier theme of *To protect and preserve,* the label had the power to precipitate the decline, but at this point the label of dementia was seen as one they would want to hide and had one that had the power to change the person, as the carer above stated, 'I wanted my mum to be the mum I knew', despite her mother having experienced quite severe cognitive problems for a long time before the diagnosis.

One carer's reaction to the diagnosis conveys his sense of anger, and then his resignation as his attempts to protect his mother from a label of dementia are unravelled:

> "I thought how dare you say…[she has dementia], I'm her son I don't think she…[has dementia]"…"and so I had to concede, I didn't want her to have dementia, be labelled with dementia" (Carer 1)

In addition to changing the person with dementia, one carer described how the diagnosis had the power to change her:

> "you're just an ordinary citizen before it's happens aren't you…I mean you just you become a different person or at least you see the world in a different way." (Carer 8)

Carers reactions to the timing of the diagnosis were mixed. Some felt that the hospital setting was not appropriate,

> "I don't think it was right for either of us. I think it was extremely abrupt and I was in a real state. And so was she. And I think, I actually think that it wasn't properly considered," (Carer 12)

Others wished the diagnosis had been made earlier and reflected on what they might have done differently,

> "Oh overdue I'd say, yeah, I needed that [diagnosis] well before it [hospital admission], we needed to know what was the matter with her" (Carer 3)
>
> "I think if we'd had a diagnosis, say, a year earlier, it would have been better for us. It probably wouldn't have made any difference to him" (Carer 7)
>
> "I'd have preferred it earlier. Earlier with either him making me aware of it to get him looked at earlier and then I think, yeah by the time then we suspected… So, yes, I do wish it was done earlier, because I could have taken more preventative measures at home" (Carer 9)

Whilst for others the timing felt right and knowing earlier may have been worse:

> "I don't think mum would have taken it earlier, if I'm honest" (Carer 11)
>
> "I don't know if it would have made any difference having that diagnosis earlier. I think it might have made it actually a little bit worse because I would have been keeping her at home. I would have tried to keep her at home as long as she could, because I think

> once someone goes into a care home it takes away a lot of their own individuality." (Carer 10)

Again, the importance placed on the independence of the PLWD is reflected in the carer's comment above, as they equate having an earlier diagnosis with an increased possibility of not being able to support the PLWD at home and earlier institutionalisation.

In another instance a carer felt the diagnosis was only made in order to facilitate the PLWD's discharge from hospital.

> "they just needed to diagnose and call it something, that's how we felt…they needed to have the diagnosis to say to a care home look, this man's got whatever, and that's because they didn't really have one. So I almost felt it was, well we don't really know, so we're going to call it this, that's how we felt" (Carer 4)

This could represent a reluctance on the part of the carer to accept the diagnosis or the consequence of a diagnosis made at a time when the carer was not prepared or expecting it.

This realisation that the world was changing, for the person and for the carer, was also reflected in the way other carers reacted to the diagnosis, "I felt sad for her, because I thought, oh my God, she's been through so much", "Stressed because…I know the inevitable decline with dementia" and "you suddenly realise you're in for the long haul, that your life probably isn't going to be your own".

Although a few carers struggled to accept the diagnosis, for most this marked a point where life did change and as the bubble of normalisation burst, they worked out what happens next.

Theme 4: What happens next?

This theme describes life after the diagnosis for the carer and PLWD. The first sub theme – *'The doors close'* represents the struggle carers faced to find help and support post diagnosis. The second sub theme – *'Paying the price'* describes the impact of the efforts of carers to preserve the independence and autonomy of the PLWD. In the same way that the *'Fear of talking about dementia'* meant there were missed opportunities in the pre-diagnosis period, the third post diagnosis sub theme – *'Still not talking'* describes how fear continued to prevent a conversation between the person and carer post diagnosis.

The doors close

In the weeks and months following the diagnosis many carers felt abandoned and alone. They described being given the diagnosis and then being left to work out what they needed to do by themselves, as the carer below describes,

> "I assumed that there would be more help…I've had to carve, literally carve my way through finding out what's out there…But there was a point right at the very beginning when there was nothing. I just couldn't see my way forward. I didn't know where we were going… we'd got the diagnosis but there wasn't a clear route where, OK, now what do I do with this diagnosis?" (Carer 5)

In addition to the struggle of finding support, this carer questioned what to do with the actual label of the diagnosis. Whereas in earlier themes the diagnosis had the power to precipitate decline or change the person and carer, it appeared that post diagnosis it did not have the power carers expected it would have to open doors and support them. Carers described 'doors closing', and compared the diagnosis to other medical diagnoses, with the expectation that the same level of help and support would be forthcoming.

> "At least when someone gets a cancer diagnosis there's some understanding of what the disease is going to do…and it's just as devastating, and it's not treated like it's an illness either…if you have any other illness, then your care is paid for." (Carer 7)

Others attributed the lack of interest to the incurable nature of dementia and the way society care for older people:

> "I just thought, well this is a medical issue, what help can I get? And that was the wrong question. It was, what am I going to do? It took me quite a while to understand it's all me, there isn't anybody else out there… So you're getting an awful lot of shut doors" (Carer 5)

> "They [the doctor] lose interest, they're not interested, there's nothing they can do. One of the things that's almost the worst thing…the doors close when you have dementia." (Carer 8)
>
> "it was in the paper today how bad we are for looking after our elderly… just can't as a society…I think we're a bit lacking in that department for looking after them" (Carer 3)

The perceived lack of available support was confirmed by the HCPs that carers were in contact with, “they referred me to…a dementia advisor but all he was really saying is, well, it’s going to get worse and worse and you’ll just have to live with it”, “I just said, so what’s going to happen now, and she [the doctor] basically said nothing. There wasn’t anything and she just said, well you can be referred to social services”.

This led carers to question the value of the diagnosis,

> “even with a diagnosis it doesn’t necessarily help the person who’s diagnosed if they don’t want to know. Even if you're a carer knowing isn’t, … it didn’t help me with knowing what I should do. You can have a diagnosis but what does that mean you do as a carer?” (Carer 5)

> “My mother had a diagnosis, but it didn’t actually help. So, we give people a diagnosis, so what? And then we say, and you’re going to get worse and worse and you’ll die and there’s nothing we can do about it, except stick you in a home and wait for you to die.” (Carer 12)

Carers described how they used the internet and books to find out more about dementia, what to expect and what support they were entitled to receive. A few carers wished they had known more about dementia to help them recognise what was happening, but most wished they had had more information about the progression of the disease and how to care for and communicate with the PLWD so that they could have done more for the PLWD or put in place practical measures like power of attorney.

> “I do think once we’d had the diagnosis, it would have been really nice if someone had come and had a chat with [PLWD] and me and talked about exactly how [he] was and how best for us to talk to him. It’s lucky that I came across this book that I found helpful, but I think if I hadn’t, that would have been not so good.” (Carer 7)

Although some carers felt this information might have been helpful to know before their loved one developed dementia, as one carer explained, unless you know you are going to become a carer for a PLWD you may not see this information as relevant for you.

> “if somebody had said, look right from now on you're going to be the carer, she’s not going to get better, you need to know about this, that would have helped me. But at the time I didn’t know I was going to be a carer.” (Carer 5)

Paying the price

As in the time before diagnosis, carers' ultimate concerns were still to protect the PLWD and preserve their independence for as long as possible, but there seemed to be a higher price to pay for this in the post diagnostic period, both for the carer and the PLWD. Either due to the length of time carers managed before the diagnosis or the physical illness which had led to the admission, PLWD had significant needs when it came to discharge from hospital. Whereas previously carers were able to make decisions related to what they thought the PLWD would want, they now found themselves in a position where others had opinions about what they should do:

> "the consultant said to me, if you take her home, it's at your own risk…I think once you make that decision, that you're going to go back home, that is when people are like, oh well, it's up to you then." (Carer 10)

> "I had an enormous amount of pressure from the discharge nurse, no, no, please, put her into a care home, it'll be much easier." (Carer 12)

Carers thought that for health care professionals, safety was prioritised over quality of life, but as the previous theme of *'The doors close'* demonstrates, carers now felt less supported as they tried to preserve the person's independence. Some carers went to great lengths to preserve the wishes of the person to be at home for as long as they could, sometimes in the face of strong opinions from family or friends that the person they cared for should move to a care home.

> "It used to upset me a lot when friends, relatives used to say, oh, you're not going to cope, you're doing yourself harm, why don't you take her into a care home… it used to really upset me and I'm glad I didn't listen to them anyway." (Carer 6)

> "a lot of people say to me "Oh you should think about a residential.." I think what they were doing they were projecting their problems and so because they couldn't deal with it and they were saying you can't do this, you've got to think of her and don't be a martyr… it was tough but I coped and I'm glad I've done it now, we're coming to the very end of it all I think" (Carer 1)

But not all carers had the resources or were able to support the person at home as they would have wished, often resulting in feelings of guilt:

> "It's a really hard thing to live with. So I think I've got a lot of guilt from that point of view, that she's ended up where she is, and it's not where she wants to be" (Carer 10)

> "it's my fault, it's because she's been independent and we've kept her going and she's been safe, she hasn't used the system,…if she'd had a carer all this time and used the system and not been independent and proud and had people going to help her…it would have been in place for her…that's very sad to me, that somebody who's tried hard and been independent is now really paying a price for being that person." (Carer 2)

The real conflict in the guilt the carer above feels is evident. By resisting using 'the system' (social services) and providing care herself for the PLWD, she had been respecting their wishes. Now as the person needs to move to a care home, she reflects on whether the process would be less traumatic for the PLWD if she had already been 'in the system'. But this would have meant not being 'independent and proud' and suggests that the two things – having help from social services and being independent and proud are not compatible.

There was also a price to pay in the relationship between the carer and the PLWD.

> "I was very practical …Rather than the emotional side of it. But sometimes that's the way you cope, isn't it?" (Carer 10)

> "And becoming a carer changes the dynamics, the power dynamics that, she didn't like but she was completely dependent." (Carer 5)

> "she wasn't happy a lot of the time and I wanted her to be. And I think I could have made her happier for longer. I didn't give her enough attention and I was just so exhausted all the time. And I'm really glad I did what I did but I wish I'd done more." (Carer 12)

Meeting the increasing needs of the PLWD could result in carers becoming task-orientated and at the same time facing resistance from the PLWD as they strived to retain their own

independence. Although carers had been caring for the PLWD for a long time before the diagnosis, the diagnosis also formalised their role as 'carer'.

Still not talking

In the same way that carers struggled to initiate conversations about their concerns in the pre-diagnosis period, very few spoke to the PLWD about their diagnosis afterwards.

Very few doctors disclosed the diagnosis to the PLWD. One carer described how the doctor, "…was trying to just speak in code so [PLWD] didn't know". This carer had to tell the PLWD the diagnosis themselves, taking an opportunity that presented itself when the PLWD showed them a magazine article about Alzheimer's disease and expressed concern that they had many of the same symptoms. However with hindsight this carer wondered whether they had done the right thing,

> "I think I've taken another little bit of her confidence away by telling her if I'm honest, because since we had that conversation, she has got worse… which I'm upset about because I don't want to do that." (Carer 11)

But most carers did not discuss the diagnosis with the PLWD. This avoidance of the topic often resulted in carers being unsure as to whether the person knew the diagnosis, whether they wanted to know or had not understood the diagnosis.

> "I hoped she didn't hear it. She was going deaf…" (Carer 12)

> "I don't know if he would understand, and if he did, I don't know, to be honest, about that" (Carer 4)

> "She didn't really understand it to be honest. They said it to her, but I don't really think, because even today, she doesn't know she's got dementia… But I don't think it would have helped my mum, to know really what she was suffering from…I think it would have frightened her." (Carer 10)

This again raised conflict in carers where on the one hand they hoped the PLWD did not know their diagnosis as it may invoke fear and on the other recognised how knowing might have helped the PLWD and might have relieved their fear, but as one carer said, "I didn't know how to raise it".

> "I think in a way it might have been a relief because she would then have known what was making her fuzzy." (Carer 12)

> "I mean if you lay there and you think your mind's going, you might really be frightened, whereas if someone says "oh mum this is old age dementia", maybe you'd go "I knew it was something"… but you don't get anybody talking to you about it" (Carer 3)

Despite recognising that knowing the diagnosis might help her mother and using this to reassure her mother in her imagined interaction, the carer above had not spoken to her mother about it, possibly believing it was someone else's responsibility to do this. A few carers worried that the person's fear of the diagnosis might result in them harming themselves:

> "she said, 'well I'll tell you what, that won't be taking me. I won't wait for that to get me' she said. And I went, Mum, you could go another ten years before you get any worse...because I'm thinking, don't top yourself… And so when she said it, that's the thought I got…don't do anything stupid, Mum." (Carer 11)

> "We never mention the word dementia and I don't want anyone to mention [it]. We've watched programmes about Alzheimer's and he says to me, 'that must be so terrible, if anything like that ever happened to me, I'd do that' he says (carer draws her finger across her throat). So Alzheimer's for him is something that just happens to other people, fortunately he doesn't have Alzheimer's." (Carer 8)

In addition to the PLWD's fear, the carer's own denial and fear is evident above as she does not want the word 'dementia' mentioned and makes comparisons to downplay the severity of the sub-type of dementia the PLWD has, compared to Alzheimer's disease. It was apparent amongst all carers that by continuing not to talk about dementia, they were preserving some of the normalisation bubble that had offered protection in the pre-diagnosis period.

Discussion

This study provides a unique insight into a group of carers of people who were diagnosed with dementia when they were not actively seeking help for a diagnosis. In common with carers in previous reviews of pathways to a dementia diagnosis, carers in this study moved through a cyclical process of noticing changes in the PLWD and seeking explanations for these. However, in these reviews carers and PLWD reach a point where increasing changes cannot be normalised and the observations of others, support from within the informal network , a

pivotal event or crisis all lead to a decision to seek help[7,9]. Despite increasing cognitive and behavioural problems and an awareness that these might be due to dementia, carers in this study were not actively seeking help for a diagnosis. Some did consult family and friends but either found their normalisations affirmed or their concerns dismissed, a factor recognised to delay diagnosis[9,13]. Others experienced pivotal events such as the PLWD getting lost or burning saucepans that were noted in other studies to precipitate help seeking[7], yet these were still not enough for them to seek help. Instead, fear and stigma related to dementia appeared to be a strong influence on carer's desires to protect the PLWD and their way of life. Carers had negative images of dementia that included loss of self and institutionalisation leading carers to protect and preserve the independence of the PLWD and to keep them at home for as long as they could. The concepts of protecting and preserving as key roles for carers are not new. An early study of family carers found that protecting loved ones from threats to their self-image, by minimising their difficulties and maximising their sense of independence, was more important to carers than providing instrumental care and that care aimed at preserving a sense of self for older people living in a care home was an important part of the family carer role[27,28].Two types of relative – the protective relative and the decisive relative were identified in a recent study of family member's experiences as relatives of a PLWD, with the carers in the present study aligning closely with the protective relative[29]. The protective relative provided practical support to the PLWD whilst, often unconsciously, hiding and denying that changes were happening to preserve the identity of the PLWD, protect their relationship with the PLWD and their way of life. In contrast, the decisive relative acknowledges the changes and initiates decisions and actions that involve help seeking. In the absence of a decisive relative, carers in this study did not consider seeking help.

However, the protective and preservative roles of carers have both been considered potentially damaging if maintained for a long period[30]. Protecting the PLWD from what is happening to them can be seen as paternalistic and preserving the past fails to acknowledge that changes and adjustments may be needed to maintain self-esteem in the future[30]. In protecting and preserving the PLWD, carers in this study were reinforcing the denial and stigma felt by both the PLWD and the carer, particularly as carers avoided talking about dementia. Many carers based their decision not to discuss their concerns or the diagnosis on what they thought the PLWD would want or had previously expressed. But by not talking to the PLWD they were potentially removing what they had sought so hard to preserve, which was the PLWD's autonomy.

Fear that a discussion with the PLWD may confirm their own concerns and lead to help seeking

and a life changing diagnosis may be one factor that prevented discussions taking place. Fear of denial by the PLWD that places the carer in a position of seeking help without their consent may be another. Carers in previous studies have expressed the conflict they face in seeking help on another's behalf and the potential this has to damage their relationship with the PLWD[7]. Although this was not explicit for carers in this study, with hindsight, some carers wished the diagnosis had come earlier and that HCPs had initiated this, taking responsibility for seeking help out of their hands.

Such opportunities to discuss concerns and initiate an assessment were not just missed by carers. Whilst a small number of PLWD had memory assessments in the months or years before their diagnosis, most were in contact with physical health services that did not initiate the assessment process. There are well recognised barriers to dementia diagnosis in primary care including time and financial constraints, diagnostic uncertainty, concerns about disclosure of the diagnosis and a lack of support services for PLWD, carers and HCPs [31]. But stigma and therapeutic nihilism on the part of HCPs are also recognised barriers [31,32]. However, GPs also describe a nuanced, cumulative process in which a dementia diagnosis in primary care evolves, to take account of the individual circumstances of each PLWD and their families[33]. As the perspectives of HCPs were not explored in this study, this explanation of events should not be ruled out, although this contribution to protecting and preserving may also add to the stigma surrounding a dementia diagnosis. If a timely diagnosis is one which happens when a PLWD and their family express concerns and a need for help, this begs the question of what happens if they feel unable to discuss their concerns. Without a prompt or enquiry from a HCP about possible concerns, the PLWD and their carer may remain unsupported indefinitely.

The difficulties around discussing dementia also extended to the diagnostic process in this study. Despite a national case finding scheme in acute hospitals at the time of diagnosis for most of the participants, the process of assessment and diagnosis varied considerably. An evaluation of the case finding scheme in one area of England found that patients and carers were often unaware that memory assessments had taken place[34], a finding supported in this study. However other carers had to use the opportunity to push for assessment and diagnosis, reflecting the variability with which the scheme has been implemented[35], but again suggesting that open conversations about memory concerns and assessment were not taking place. This continued with diagnosis disclosure.

The practice of disclosing the diagnosis over the phone to the carer was common, leaving the carer unaware as to whether the PLWD had been told. A majority of people would want to be

told their diagnosis if they had dementia, a trend that has increased over time[36]. Although in some studies, carers of PLWD were less in favour of disclosure to the PLWD, despite wishing to know themselves if they had the disease[37]. A review of dementia disclosure practice revealed that only 34% of GPs and 48% of specialists always told the PLWD their diagnosis, with 89% of GPs and 96% of specialists always telling the PLWD's family[38]. Concerns around initiating assessment, diagnosis and disclosure included when the person and/or their family were in denial and when families expressed concern but the person themselves was not worried. The practitioner's own confidence and beliefs about dementia, the health system they worked in, the awareness and circumstances of the PLWD and stigma also contributed to decisions about whether to disclose the diagnosis[38]. It is recommended that disclosing a diagnosis of dementia should be a process rather than a single event, with the opportunity to discuss the possibility of a diagnosis before it is confirmed[37]. Whether an acute hospital admission is the most appropriate setting for this requires further research, however what is clear is that it does require more open and honest communication between HCPs, PLWD and their carers.

It has been suggested that to be willing to diagnose and disclose dementia, HCP's need to "appreciate the value of the diagnosis" for the PLWD and their family (p1615)[36]. However, very few carers in this study described considering seeking help for a diagnosis, suggesting this was not an option they saw as being valuable to them, with some carers questioning the value of diagnosis after they had received it. This was largely due to the lack of support they felt in the post diagnosis period, a finding supported in previous studies[8]. The benefits of an early diagnosis may be outweighed if the PLWD and their carers are given a diagnosis but left without support[39]. The biomedical model of dementia is the one most often portrayed in the media, with a focus on the progressive nature of the disease and the need to find a cure[40]. Alternative models with a focus on living well with dementia tend to reside largely within policy and research and less within popular media[41]. Without positive images of how PLWD and their families are supported to live well post diagnosis, carers may see little benefit in seeking a diagnosis, which in their eyes, results in a stigmatising label rather than support. Self-stigma and label avoidance have been associated with reduced help seeking for mental health concerns[42] and for carers in this study, the label of dementia had various meanings. It had the power to precipitate decline and make real the difficulties PLWD were experiencing in the pre-diagnosis period. It had the power to change the PLWD and the carer at diagnosis, was something to be concealed or seen as necessary for hospital discharge to happen. Post diagnosis the carer's role was formalised and although some carers felt that knowing the diagnosis would not benefit the PLWD, they hoped that the label would open doors and lead

to support for them as a carer. As close family members and carers are most often the people who initiate help seeking for a dementia diagnosis, to encourage help seeking, the benefits of a diagnosis both to the PLWD and themselves as carer need to be clear.

Strengths and limitations

This is the first study to consider the dementia diagnosis help seeking process from the perspective of carers who were not actively seeking help and allows an insight into factors influencing help seeking decisions in a group of people who are often difficult to identify and support. The role of stigma in preventing discussion about dementia suggests this may be an important factor preventing help seeking, that extends to HCPs as well as carers and PLWD. A limitation of this study is the absence of the voice of the people with dementia. The original study aim was to explore the perspectives of people diagnosed during or following a hospital admission in addition to their carers, but we were unable to recruit any PLWD to the study. It is a criticism of dementia literature, and that focused on stigma and dementia, that the carer voice dominates these narratives and as such may serve to reinforce the stigma experienced by people with dementia [43]. But by understanding the experiences of these carers, and particularly their difficulties in talking about dementia, future research and development should aim to support carers to talk about their concerns and in turn encourage conversations and the voice of the PLWD to be heard. Stigma has been recognised as a barrier to participation in dementia research and may have contributed to the difficulty in recruiting carers for this study, particularly in the days or weeks following diagnosis [44]. It is also possible that the carers recruited from JDR may differ from other dementia carers, but their experiences are no less valid than those of people who do not wish to participate in research, and research databases such as JDR provide a useful way to recruit participants in hard to reach populations.

Conclusion

With policy imperatives and interventions to increase timely diagnosis of dementia across the globe, understanding the experiences of those who do not seek help is increasingly important.

Increased public awareness of dementia meant that most carers considered dementia the possible cause for the difficulties the PLWD was having. But increased awareness may lead to increased fear[45]. Stigma related to images of dementia as a disease that takes away independence and identity prevented discussion about dementia between carers and the PLWD in this study. This was exacerbated by a lack of open discussion about memory concerns

between HCPs and carers as they encountered health services.

Carers chose to create a bubble of normalisation around the PLWD to protect and preserve their independence rather than discuss their concerns and seek help. The lack of support post diagnosis serves to further reinforce negative images that 'nothing can be done' for a PLWD. If we are to encourage people to seek help for a dementia diagnosis then positive images of people living well with dementia and being supported to maintain their independence and autonomy need to be the mainstream, rather than the catastrophic views often portrayed in the media [46]. Service provision would need to match expectations however, for the benefit of diagnosis to be valued. Future interventions targeted at supporting family members to discuss concerns about dementia with their loved ones may result in a diagnostic process that is governed by the person and their carer and results in a diagnosis that comes at the right time for them. Health care professionals also need the confidence to talk openly about dementia with patients and their families to encourage those who have concerns to share these and seek help earlier.

Statement of ethical approval

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Chapter 6: Characteristics of people referred to an inner London memory clinic by primary care and acute hospital pathways

This chapter presents the findings of the quantitative phase of the study. This phase aimed to examine the characteristics of people referred to a memory clinic to determine if differences existed between people referred by their GP and people referred by the acute hospital. It was considered that people referred by their GP were more likely to have sought help for their problem themselves or with the support of a carer and that people referred by the acute hospital had not sought help previously in primary care. As little is known about people who do not seek help for memory concerns, an analysis of memory clinic referrals by referral source helped to identify differences in demographic and clinical characteristics between people referred by different sources. The findings of this phase of the study were able to complement the findings of the systematic review and qualitative phase in the integration of findings in Chapter Seven. This chapter is in the format of an article for publication. The article has been submitted for publication and is currently under review. The article includes a brief introduction to the topic and methods, which have been covered in greater depth in Chapter One and Chapter Three. The findings of the quantitative analysis are presented followed by a discussion of the findings.

STATEMENT OF CO-AUTHORS of JOINT PUBLICATIONS

TO WHOM IT MAY CONCERN

Title of publication: Characteristics of people referred to an inner London memory clinic by primary care and acute hospital pathways

Name of candidate: Michelle Parker

Title of research thesis: We need to talk about dementia: Stigma and the role of the social network in preventing help seeking for a diagnosis of dementia

Name of first supervisor: Professor Leanne Aitken

We, the undersigned, co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication

The candidate's contribution included:

- Sourcing the data
- Cleaning and coding the data
- Data analysis
- Interpretation of the data
- Writing and revision of the manuscript

The research and writing of the paper were conducted with methodological and editorial advice from Professor Leanne Aitken, Dr Juanita Hoe and Dr Sally Barlow.

Characteristics of people referred to an inner London memory clinic by primary care and acute hospital pathways

Abstract

Background: Encouraging timely diagnosis of dementia has become a global policy imperative. Understanding referral patterns and clinical characteristics of people referred to memory clinics will help to identify factors influencing service use and help- seeking.

Objectives: To examine characteristics of people referred to a memory clinic by their General Practitioner (GP) and people identified and referred via the acute hospital. To determine factors associated with a dementia diagnosis and survival following diagnosis.

Design: Retrospective cohort analysis of 1830 people referred to an Inner London memory clinic in England (January 2013- June 2016).

Method: Bivariate analysis explored differences in age at referral, gender, ethnicity, diagnostic outcome, dementia severity at diagnosis, number of hospital admissions in 12 months pre- and post-referral and survival at 6- and 12-months post referral by referral source. Binary logistic regression identified factors associated with dementia diagnosis and survival following dementia diagnosis.

Results: People referred via the acute hospital were significantly more likely to be older, white and diagnosed with dementia. People referred by their GP were significantly more likely to be Asian, diagnosed with cognitive impairment or be cognitively intact. Age at referral was positively associated with dementia diagnosis. Three hospital admissions in 12 months pre-referral was negatively associated with diagnosis. Factors independently associated with survival at 12 months following diagnosis included age at referral, ethnicity, sub-type or severity of dementia and hospital admissions in 12 months post referral.

Conclusion: People diagnosed with dementia were more likely to be identified during acute hospital admission, and people referred by their GP were less likely to be diagnosed with dementia. There were significant differences in ethnicity and referral pathway, with people from Black, Asian and Minority Ethnic (BAME) backgrounds more likely to be referred by their GP. This may indicate differences in help-seeking between different groups within a community, requiring nuanced approaches to identify undiagnosed dementia and encourage help-seeking.

Keywords: Dementia, Diagnosis, Help-seeking, Memory Clinic

Introduction

It is estimated over 50 million people worldwide are living with dementia, and this is likely to increase to 152 million by 2050[1]. Globally up to 50% of people in high-income countries and up to 95% of people in low- and middle-income countries are living with symptoms of dementia without a formal diagnosis[2]. Improving diagnosis rates and an emphasis on encouraging timely diagnosis has become the focus of dementia policies and strategies worldwide[3]. Whilst benefits of a formal diagnosis, particularly at an early stage remain unclear, diagnosis allows access to dementia-specific care and support, prescription of acetylcholinesterase inhibitors and enables people living with dementia and families to plan for the future[4,5].

Primary care services are the first point of contact in most countries for people and their families concerned about memory problems; however, diagnosis often takes place in specialist services such as memory clinics[5]. The structure and function of memory clinics vary, understanding referral patterns to memory clinics and the clinical characteristics of people referred can help to identify factors influencing service use and help seeking behaviour[5,6].

The National Dementia Strategy and subsequent policies in England have been accompanied by the introduction of financial incentives to improve diagnosis rates in primary and secondary care[7,8]. The acute hospital admission is an opportunity to recognise undiagnosed dementia in people who have not sought help in primary care[9], with estimates that at any one time a typical 500 bed acute hospital in the UK - will have at least 70 inpatients with undiagnosed dementia[10]. Current research on people admitted to acute hospitals with undiagnosed dementia has been limited to prevalence studies[11-13], with this group being identified as older and frailer than those with a recognised dementia diagnosis on admission to hospital[13]. People with dementia admitted to acute hospitals are at greater risk of adverse outcomes[14]. Sharing of data between primary and secondary care services varies and can mean that a previous diagnosis of dementia is not always known to acute hospital staff on admission[15]. But the identification of dementia can assist in reducing adverse outcomes with appropriate care and discharge management, improving the overall quality and experience of care for people living with dementia and their families[10]. A diagnosis of dementia earlier in the disease trajectory with access to services and advance planning may also reduce future hospital admissions[10]. Consequently, understanding the characteristics of people admitted to an acute hospital with undiagnosed dementia may help to identify opportunities for earlier help seeking and diagnosis.

We examined characteristics of people referred to a memory clinic to determine if those referred via their primary care doctor or general practitioner (GP) differed from those identified and referred by the acute hospital. We then determined which factors were associated with receiving a dementia diagnosis and which factors were associated with survival following a dementia diagnosis.

Methods

This study was a retrospective cohort analysis of people referred to a memory clinic at an urban university hospital in inner London, England. The population of the borough has an average age of 31.3 years and is one of the most ethnically diverse populations in the UK[16].

The memory clinic received referrals for all people requiring a dementia assessment within the borough. This dataset allowed for direct comparison between people referred by GPs and the acute hospital. Data were extracted from the memory clinic database and corresponding electronic patient records for consecutive referrals between January 2013 - June 2016. This time period coincided with the introduction of a case finding approach in the acute hospital, whereby all patients aged 75 years and over, admitted as an emergency, received a cognitive assessment and onward referral to the memory clinic if there were any concerns[17]. From June 2016 onwards GP referrals to the memory clinic were managed separately within primary care, so data did not exist within the database to allow comparison of patient characteristics between referral sources.

Data extracted included age at time of referral, gender, ethnicity, diagnostic outcome, dementia severity at diagnosis, number of hospital admissions in 12 months pre and post referral and survival at 6- and 12-months post referral. The hospital trust anonymised all data prior to analysis. Full National Health Service (NHS) ethics approval or individual consent was not required, but approval from the Health Research Authority in England (HRA) was granted (IRAS 242277).

Data related to previous medical history were extracted from electronic patient records but could not be used as it was not possible to separate acute from chronic problems. Hospital admission data in the 12 months pre and post referral were used to indicate morbidity, as higher levels of morbidity are associated with higher levels of emergency admission[18]. For people referred from the acute hospital, the admission which resulted in the referral was not counted as a prior admission. Although the data did not differentiate between emergency and planned admissions, almost all admissions were to acute general medical specialties, general

surgery or trauma and orthopaedics, suggesting the majority were emergency admissions. Information on the coding of data extracted can be found in Appendix 15.

All referrals were for dementia assessment, and the first referral to the clinic for each patient was included. Multiple referrals for the same patient, referrals for reassessment, referrals not accepted or referrals for people with an existing dementia diagnosis were excluded. Four records were excluded due to missing essential data e.g. referral source.

Data analysis was carried out using SPSS v25 (IBM Corp. Armonk. NY). Bivariate analyses of data were conducted, and characteristics of different referral groups compared using Chi-square tests (or Fisher's exact test when appropriate) for nominal variables and ANOVA for continuous variables. When the Chi-square/ Fishers exact statistic was significant, standardised residuals were used to determine where the difference lies (using a cut off of +/- 2)[19]. Binary logistic regression was performed to explore factors associated with the likelihood of a dementia diagnosis and factors associated with the likelihood of survival at 12 months post referral, for those diagnosed with dementia. Variables significant at the level of $p<0.20$ were included in the multivariable analysis (for details of the variables used see Chapter Three, section 3.7.5). To identify factors associated with a dementia diagnosis the model included a sample of 1500, as those unable to be assessed or refused assessment were excluded. To identify factors associated with survival at 12 months post dementia diagnosis, 704 people diagnosed with dementia following their memory clinic assessment were included in this model.

Results

A total of 2637 people were referred to the memory clinic during the study period, with 1830 first referrals included in the final analysis.

Most patients were referred to the clinic by their GP (66%), and approximately one-third of patients were diagnosed with dementia (Table 6.1). The average age of patients was 77 years, with slightly more female patients and a mix of ethnicities (Table 6.1).

Table 6.1 Characteristics of the sample by referral group

	GP Group (n=1201)	Hospital Group (n=493)	Other Group (n=136)	P value (test)	Total sample (n=1830; % in total sample)
Age at referral (m±SD)	75.1 ± 10.6	81.9 ± 8.4	76.7 ± 10.9	<0.001 (One-way ANOVA)	77.1 ±10.5
Gender n (%)					
Female	651 (64.3)	289 (28.5)	73 (7.2)	2.925 (χ2)	1013 (55.4)
Ethnicity n (%)				<0.001 (χ2)	
White	424 (53.6)	309 (39.1)	58 (7.3)		791 (43.2)
Asian/Asian British	438 (76.6)	95 (16.6)	39 (6.8)		572 (31.3)
Black/African/Caribbean/Black British	244 (73.1)	62 (18.6)	28 (8.4)		334 (18.3)
Mixed/multiple ethnic group/ other/ not stated	95 (71.4)	27 (20.3)	11 (8.3)		133 (7.3)
Diagnostic outcome n (%)				<0.001 (χ2)	
Alzheimer's Disease diagnosis	124 (72.5)	37 (21.6)	10 (5.8)		171 (9.3)
Vascular Dementia diagnosis	164 (64.8)	69 (27.3)	20 (7.9)		253 (13.8)
Mixed dementia diagnosis	117 (68.0)	46 (26.7)	9 (5.2)		172 (9.4)
Other dementia diagnosis	45 (41.7)	46 (42.6)	17 (15.7)		108 (5.9)
Cognitive impairment diagnosis	289 (74.5)	66 (17.0)	33 (8.5)		388 (21.2)
Non-dementia diagnosis	121 (56.0)	78 (36.1)	17 (7.9)		216 (11.8)
Cognitively intact	159 (82.8)	27 (14.1)	6 (3.1)		192 (10.5)
Refused assessment/ did not attend	114 (65.9)	51 (29.5)	8 (4.6)		173 (9.5)
Unable to assess as too unwell/ died/ unable to contact	68 (43.3)	73 (46.5)	16 (10.2)		157 (8.6)

GP: General Practitioner; m: mean; SD: standard deviation

Comparisons between referral sources

In the bivariate analysis of the total sample there were significant differences in patient characteristics between referral sources (Table 6.1). People referred to the memory clinic by the acute hospital were likely to be older. People referred by the acute hospital were more

likely to be of white ethnicity, while those referred by the GP were more likely to be of Asian ethnicity (Fig 6.1a). Those referred by the acute hospital were more likely to receive a diagnosis of 'Other Dementia', a 'non-dementia diagnosis' or were 'unable to be assessed', compared to those referred by the GP who were more likely to receive a diagnosis of 'cognitive impairment' or be 'cognitively intact' (Fig 6.1b).

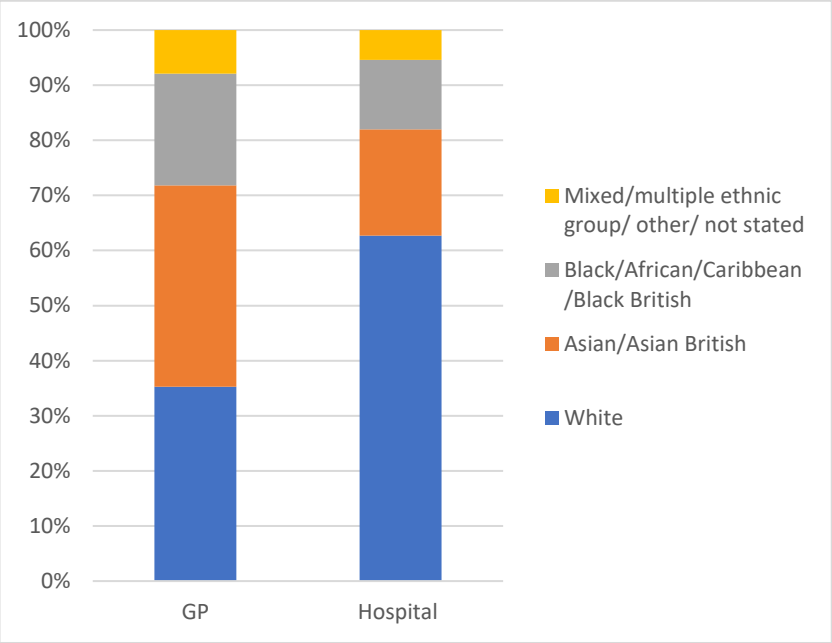

Fig. 6.1a Ethnicity by referral source

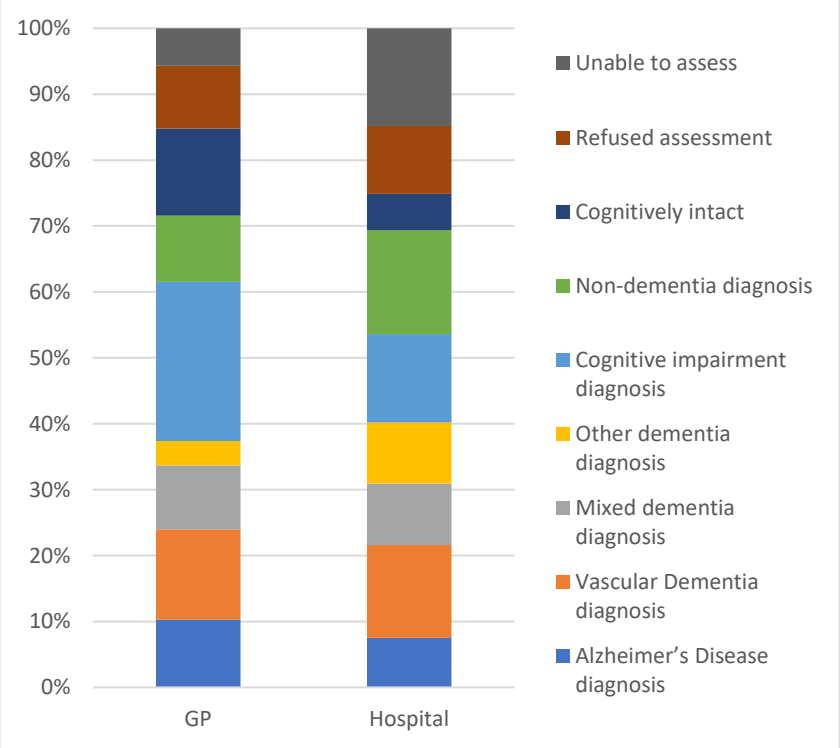

Fig.6.1b Diagnosis by referral source

The subset of the sample receiving a dementia diagnosis (n=704) were analysed separately. Significant differences between referral sources remained (Table 6.2). When compared to people referred by their GP, those referred by the acute hospital were significantly older, more likely to be of white ethnicity and more likely to be diagnosed with 'Other Dementia'. They were also more likely to have severe dementia at time of diagnosis, to have died 12 months post referral and to have had 1 or more admissions in the 12 months prior to referral and 1,3,4 or more admissions in the 12 months after referral.

Table 6.2 Characteristics of the sample diagnosed with dementia by referral source

	GP Group (n=450)	Hospital Group (n=198)	Other Group (n=56)	P value (test)	**Total sample (n=704; % in total sample)**
Age at referral (m±SD)	79.9 ± 8.3	83.5 ± 7.5	79.3 ± 9.7	<0.001 (One-way ANOVA)	80.92±8.4
Gender n (%)				0.185 (χ2)	
Female	257 (63.3)	122 (30.0)	27 (6.7)		406(57.7)
Ethnicity n (%)				<0.001	
White	181 (54.8)	120 (36.4)	29 (8.8)	(χ2)	330 (46.9)
Asian/Asian British	134 (71.3)	39 (20.7)	15 (8.0)		188 (26.7)
Black/African/Caribbean/Black British	98 (73.1)	27 (20.1)	9 (6.7)		134 (19.0)
Mixed/multiple ethnic group/ other/ not stated	37 (71.2)	12 (23.1)	3 (5.8)		52 (7.4)
Diagnostic outcome				<0.001	
Alzheimer's Disease diagnosis	124 (72.5)	37 (21.6)	10 (5.8)	(χ2)	171 (24.3)
Vascular Dementia diagnosis	164 (64.8)	69 (27.3)	20 (7.9)		253 (35.9)
Mixed dementia diagnosis	117 (68.0)	46 (26.7)	9 (5.2)		172 (24.4)
Other dementia diagnosis	45 (41.7)	46 (42.6)	17 (15.7)		108 (15.3)

Severity of dementia at time of diagnosis n (%)				0.005 (χ2)	
Mild	143 (70.8)	42 (20.8)	17 (8.4)		202 (28.7)
Mild-moderate	61 (67.8)	24 (26.7)	5 (5.6)		90 (12.8)
Moderate	180 (64.1)	82 (29.2)	19 (6.8)		281 (39.9)
Moderate to severe	31 (52.5)	21 (35.6)	7 (11.9)		59 (8.4)
Severe	8 (32.0)	15 (60.0)	2 (8.0)		25 (3.6)
Not confirmed	27 (57.4)	14 (29.8)	6 (12.8)		47 (6.7)
Mortality at 6 months post referral n (%)				<0.001 (χ2)	
% alive at 6 months	438 (66.0)	171 (25.8)	55 (8.3)		664 (94.3)
Mortality at 12 months post referral n (%)				<0.001 (χ2)	
% alive at 12 months	413 (67.0)	152 (24.7)	51 (8.3)		616 (87.5)
Hospital admissions in 12 months pre- referral n (%)				<0.001 (χ2)	
Zero admissions	383 (70.8)	117 (26.1)	41 (7.6)		541 (76.8)
1 admission	47 (45.2)	46 (44.2)	11 (10.6)		104 (14.8)
2 admissions	18 (43.9)	21 (51.2)	2 (4.9)		41 (5.8)
3 admissions	1 (14.3)	6 (85.7)	0 (0.0)		7 (1.0)
4 or more admissions	1 (9.1)	8 (72.7)	2 (18.2)		11 (1.6)
Hospital admissions in 12 months post- referral n (%)				<0.001 (χ2)	
Zero admissions	363 (68.0)	130 (24.3)	41 (7.7)		534 (75.9)
1 admission	54 (54.0)	40 (40.0)	6 (6.0)		100 (14.2)
2 admissions	20 (62.5)	7 (21.9)	5 (15.6)		32 (4.5)
3 admissions	9 (42.9)	11 (52.4)	1 (4.8)		21 (3.0)
4 or more admissions	4 (23.5)	10 (58.8)	3 (17.6)		17 (2.4)

GP: General Practitioner; m: mean; SD: standard deviation

Comparisons between Ethnic Groups

People of white ethnicity were more likely to be diagnosed with Alzheimer's disease than other ethnic groups and less likely to be diagnosed with cognitive impairment than other ethnic groups (Table 6.3). People of Asian ethnicity were more likely to be diagnosed with cognitive impairment, less likely to be diagnosed with Alzheimer's disease or mixed dementia

and more likely to be moderate to severely impaired than other ethnic groups at the time of diagnosis. People of Black ethnicity were more likely to be diagnosed with cognitive impairment and less likely to receive a non-dementia diagnosis.

What factors are associated with a diagnosis of dementia?

Age at referral and three hospital admissions in the 12 months pre-referral were independently associated with receiving a dementia diagnosis (see Table 6.4). For every increase in age by one year, patients were 1.1 times more likely to be diagnosed with dementia. People with three hospital admissions in 12 months pre-referral were 0.38 times less likely to have received a dementia diagnosis than those with zero hospital admissions pre-referral.

What are the factors associated with survival in those diagnosed with dementia?

Age at referral, ethnicity, dementia sub-type, severity of dementia and hospital admissions in 12 months post referral were independently associated with survival at 12 months after referral in those diagnosed with dementia (Table 6.5). Older people and those of white ethnicity were less likely to have survived. People diagnosed with Alzheimer's disease were more likely to have survived than all other dementia types. There was no consistent relationship between severity of dementia at diagnosis and survival at the lower levels of severity, but those with moderate to severe or severe dementia at diagnosis were less likely to have survived at 12 months post referral. There was also no consistent relationship between the number of hospital admissions in the 12 months post referral and survival.

Table 6.3 Ethnicity, outcome of clinic assessment and severity of dementia at diagnosis

	White (n=791)	Asian/Asian British (n=572)	Black/African/ Caribbean/ Black British (n=334)	Mixed/multiple ethnic group/ other/ not stated (n=133)	P value (test)
Diagnostic outcome n(%)					<0.001 (χ2)
Alzheimer's disease	96 (12.1)	35 (6.1)	26 (7.8)	14 (10.5)	
Vascular Dementia	99 (12.5)	83 (14.5)	51 (15.3)	20 (15)	
Mixed Dementia	84 (10.6)	35 (6.1)	41 (12.3)	12 (9)	
Other dementia	51 (6.4)	35 (6.1)	16 (4.8)	6 (4.5)	
Cognitive impairment	135(17.1)	143 (25)	90 (26.9)	20 (15)	
Non-dementia diagnosis	91 (11.5)	77 (13.5)	27 (8.1)	21 (15.8)	
Cognitively intact	75 (9.5)	69 (12.1)	31 (9.3)	17 (12.8)	
Refused/ did not attend	81 (10.2)	51 (8.9)	29 (8.7)	12 (9)	
Unable to assess	79 (10)	44 (7.7)	23 (6.9)	11 (8.3)	
Severity of dementia at time of diagnosis n(%)					0.010 (χ2)
Mild	96 (29.1)	52 (27.7)	45 (33.6)	9 (17.3)	
Mild-moderate	47 (14.2)	15 (8)	20 (14.9)	8 (15.4)	
Moderate	140 (42.4)	69 (36.7)	46 (34.3)	26 (50)	
Moderate to severe	23 (7)	27 (14.4)	6 (4.5)	3 (5.8)	
Severe	6 (1.8)	9 (4.8)	7 (5.2)	3 (5.8)	
Not confirmed	18 (5.5)	16 (8.5)	10 (7.5)	3 (5.8)	

Table 6.4 Logistic Regression for factors associated with dementia diagnosis

	Full model	**Final model**
	OR (95% CI) p value	OR (95% CI) p value
Age in years at referral	1.10 (1.08-1.11) <0.001	1.10(1.08-1.11) <0.001
Gender	1.0 (0.8-1.25) 0.97	
Source of referral		
GP	Reference	
Hospital	0.85 (0.64-1.13) 0.27	
Other	1.21 (0.79 – 1.86) 0.39	
Ethnicity		
White	Reference	
Asian/Asian British	0.96 (0.73-1.26) 0.76	
Black/African/Caribbean/Black British	1.20 (0.88-1.63) 0.26	
Other/ not stated	1.32(0.83-2.10) 0.24	
Hospital admission in 12 months pre-referral		
Zero admissions	Reference	
1 admission	0.93 (0.67-1.30)0.68	
2 admissions	1.34(0.78-2.31)0.29	
3 admissions	0.41(0.16-1.1) 0.07	0.38 (0.15-0.97) 0.04
4 or more admissions	1.43(0.53-3.87) 0.49	

Table 6.5 Logistic regression for factors associated with survival at 12 months post-referral

	Full model	**Final model**
	OR (95% CI) p value	OR (95% CI) p value
Age in years at referral	0.94 (0.90-0.98) 0.002	0.93 (0.90-0.97) 0.001
Source of referral		
GP	Reference	
Hospital	0.62 (0.35-1.12) 0.11	
Other	1.43 (0.47-4.37) 0.53	
Ethnicity		
White	Reference	
Asian/Asian British	1.94 (0.90-0.98) 0.06	2.14 (1.08-4.23) 0.03
Black/African/Caribbean/Black British	2.27 (0.94-5.49) 0.07	2.41 (1.01—5.78) 0.05
Other/ not stated	3.42 (0.70-16.82) 0.13	3.70 (0.78-17.81) 0.10
Hospital admission in 12 months pre-referral		
Zero admissions	Reference	
1 admission	0.96 (0.48-1.94) 0.91	
2 admissions	0.63 (0.25-1.60) 0.33	
3 admissions	0.59 (0.09-3.98) 0.59	
4 or more admissions	0.86 (0.17-4.34) 0.85	
Hospital admissions in 12 months post-referral		
Zero admissions	Reference	
1 admission	0.29 (0.15-0.54) <0.001	0.28 (0.15-0.51) <0.001
2 admissions	0.49 (0.16-1.49) 0.21	0.47 (0.16-1.40) 0.18
3 admissions	0.18 (0.06-0.52) 0.002	0.15 (0.05-0.45) 0.001
4 or more admission	0.20 (0.59-0.71) 0.01	0.19 (0.06-0.65) 0.008
Diagnostic outcome		
Diagnosis Alzheimer's Disease	Reference	
Diagnosis Vascular Dementia	0.30 (0.17-0.76) 0.01	0.30 (0.12-0.77) 0.01
Diagnosis mixed Dementia	0.24 (0.09-0.64) 0.004	0.26 (0.10-0.67) 0.005
Diagnosis other Dementia	0.17 (0.06-0.45) <0.001	0.17 (0.07-0.44) <0.001
Severity of dementia at diagnosis		
Mild	Reference	
Mild to moderate	1.06 (0.42-2.68) 0.91	0.96 (0.38-2.40) 0.96
Moderate	1.27 (0.61-2.64) 0.53	1.13 (0.55-2.32) 0.74
Moderate to severe	0.26 (0.11-0.62) 0.002	0.24 (0.10-0.59) 0.002

Severe	0.09 (0.03-0.30) <0.001	0.07 (0.02-0.23) <0.001
Not confirmed	0.90 (0.29-2.79) 0.84	0.81 (0.26-2.49) 0.72

Discussion

To our knowledge this is the first study to compare characteristics of people referred to a memory clinic via different pathways. People referred to the clinic by their GP were more likely to be of Asian ethnicity and to receive a diagnosis of cognitive impairment or be cognitively intact than to receive a diagnosis of dementia or a physical or mental health diagnosis. People referred by the acute hospital to the clinic were older, more likely to be of white ethnicity and to receive a dementia diagnosis, a physical or mental health diagnosis or be unable to be assessed following referral.

Although memory clinics in the UK are seeing more patients, the proportion of people receiving a dementia diagnosis has decreased[20]. The majority of referrals to the memory clinic in this study came from GPs and these people were more likely to be cognitively intact or have a non-dementia cognitive impairment, suggesting improvements in awareness and concern about early memory problems may have resulted in prompt help seeking. As evaluations of cancer awareness campaigns have shown, increases in GP attendance and onward referral do not necessarily result in increased diagnoses[21-23] and an intervention to encourage help seeking for memory problems in England also resulted in increased GP attendance but not increased memory clinic referrals[24]. This could have been due to GP concerns over memory clinic waiting times and availability of services, but it may also be a result of an increase in attendance from the "worried well"[24]. High levels of worry about developing dementia have been associated with the subjective report of memory concerns but no actual cognitive impairment in older adults, with the value of subjective memory concerns as an indicator of dementia being questioned[25,26]. People with subjective memory complaints attending memory clinics have also been found to have a higher prevalence of psychosocial stress[27,28]. It is possible that large numbers of people referred by their GP and not diagnosed with dementia may represent increased worry about developing dementia or high levels of psychosocial stress within a community. Such findings may indicate to service providers an increased need for mental health and psychology services in addition to awareness raising for memory problems. In communities where wider social determinants of health may be associated with poorer mental health this could be even more important[29].

It would be an oversimplification to assume that all people referred by their GP had actively sought help for memory concerns. It is possible that family members, other health professionals or the GP themselves had raised concerns which prompted referral. However, in this study all patients were contacted by memory clinic staff to arrange an appointment and had the opportunity to refuse assessment, suggesting that even if they had not sought help for themselves, they were willing to be assessed. No significant differences were found between referral sources for those refusing or not attending

People most likely to be diagnosed with dementia in the current study were more likely to be identified because of an acute hospital admission, than referred by their GP. This suggests some success of the case finding approach introduced by the government in England to identify undiagnosed dementia in acute hospitals[17]. People referred by the acute hospital were more likely to be older and of white ethnicity than people referred by their GP. Although the clinic is in a borough with a small overall proportion of white British people, there is a higher proportion of white British people over the age of 65 compared to other ethnic groups[30]. Increasing age as a risk factor for emergency hospital admissions[18], could explain why referrals from the acute hospital were more likely to be for older people of white ethnicity. However, there is evidence to suggest hospital clinicians may suspect dementia less in younger people and people from BAME groups[15]. But this finding does not explain why older people of white ethnicity had not sought help for memory concerns from their GP prior to hospital admission. The older white population in the borough have a higher propensity to social exclusion (including income deprivation, lower transport accessibility, poorer neighbourhood and household ties, poorer health and safety fears) compared to younger and BAME populations in the borough[31,32]. Older people and those with smaller social networks in deprived areas are less likely to seek help for mental health problems[33] and social networks are likely to be a key factor in help seeking for a diagnosis of dementia[34], particularly amongst people with greater cognitive impairment who rely on others for support to seek help[35].

People of Asian and Black ethnicity were more likely to be referred by their GP than people of white ethnicity in the current study, although only Asian ethnicity reached statistical significance. Previous studies have suggested that people of BAME backgrounds may be less likely to access dementia diagnostic services, have a longer delay between referral and assessment and be diagnosed with dementia at later stages[36-39]. Reviews of the barriers to help seeking for memory concerns in BAME groups have found that knowledge and awareness of dementia, particularly related to the cause of dementia, knowledge of dementia services, the stigma associated with a diagnosis of dementia and a preference for family to provide care

rather than seek medical help can prevent help seeking among older people and their carers[40,41]. A lack of cultural sensitivity amongst health care professionals, previous negative experiences of help seeking, language barriers and a lack of culturally specific services is also thought to deter people seeking help[40,41]. Interventions targeted at specific groups in a community which focus on barriers relevant for a specific population, for example the aetiology of dementia and risk factors to reduce stigma, the help available and the benefits of this, are considered to be a way to improve help seeking within BAME communities[42,43]. The work of local community organisations in raising awareness of dementia in the borough of the memory clinic in this study, including a play to tackle the stigma of dementia in South Asian communities, may have contributed to the willingness of people of Asian ethnicity in the borough to seek help from their GP for memory concerns[44]. It is suggested that knowledge and awareness of dementia generally amongst BAME groups in the UK has improved, although stigma and language remain as barriers to accessing services and that when people do seek help a lack of knowledge and cultural sensitivity in primary care may still be a barrier to diagnosis, so improvements in help seeking may be isolated to communities engaged in tackling these barriers[45]. Although overall people of Asian ethnicity in the current study were more likely to be diagnosed with cognitive impairment and less likely to be diagnosed with dementia, those diagnosed with dementia were more likely to be moderate to severely impaired at the time of diagnosis, in keeping with other studies[38]. It is possible that they faced barriers to help- seeking earlier in their disease process[40], although in general people referred by the acute hospital were more likely to have severe dementia at the time of diagnosis, suggesting barriers to help-seeking may exist across ethnic groups.

The findings of this study support those of a recent study of referrals to memory services in London, where people from BAME backgrounds accessed memory services at an equal or higher rate than the majority white population[46]. This was attributed to the success of awareness raising campaigns and increased diversity amongst general practice and memory clinic staff. A study to determine attitudes associated with help seeking for memory concerns among people in the UK from South Asian backgrounds found that the approval or expectation of help seeking amongst significant others was associated with a willingness to seek help, along with an attitude that seeking help would be useful and easy to achieve[47]. It is possible that work within the borough in this study to ensure services were culturally sensitive and easy to access[44], along with increased awareness of the benefits of seeking help amongst the wider community encouraged people with memory concerns to seek help.

Accurate data on comorbidities for this study sample was not available. But people referred by their GP were less likely to have had hospital admissions prior to referral or multiple admissions post referral, suggesting lower morbidity in this group. In contrast, those referred by the acute hospital were more likely to have admissions in the 12 months before and after referral, possibly indicating higher morbidity in this group. As these people had not been referred to the memory clinic by their GP, it may also suggest they were not regularly accessing primary care services or that their physical problems overshadowed the identification of cognitive problems in primary care. Denial, resignation, minimising problems and attributing memory problems to old age are all reasons older people do not seek help in primary care[48]. In addition, people with subjective memory problems are reported to believe GPs are too busy and should only be consulted for physical symptoms[35].

Mortality rates for people with dementia in the 12 months after diagnosis have been reported as three times higher than for people without dementia, with median survival decreasing with age[49] and the findings of the current study support this. People with moderate to severe or severe dementia at diagnosis were also less likely to survive in this study, and this has been attributed to diagnosis at later stages of the disease in other studies[49].

Patients with three hospital admissions in the 12 months before referral were about a third less likely to receive a dementia diagnosis. There could be many possible explanations for this, but recurrent illness and delirium, a common complication of dementia, may have raised suspicion of an underlying cognitive impairment prompting referral[10]. There are probable links between self-care and cognitive impairment in long term conditions such as heart failure[50] and diabetes[51], so multiple admissions for poor self-management of physical problems may also result in referral for cognitive assessment.

This study adds to a growing body of evidence aimed at understanding memory clinic populations and ensuring equality of access to services. This will be increasingly important for dementia diagnosis rates to improve. Although generalising the findings of this study to other memory clinic populations would be difficult due to the unique demographic makeup of the population studied, it highlights the need for policy makers and service providers to understand the diversity of local populations accessing memory services and the need to consider individualised approaches to support groups within communities who may not seek help. Further exploration of the extent to which memory clinic referrals result in dementia diagnoses for subgroups within a community could also reveal unmet needs in relation to

psychological or physical health problems that would be useful in the planning and commissioning of services.

Strengths and limitations

Comparing data for people referred to a memory clinic from both the GP and acute hospital setting is a strength of this study. Data used were limited to those collected during routine clinical care, this will allow the study to be replicated within other memory services. As the clinic was situated in a large UK NHS trust this ensured admissions to hospitals in three local boroughs were captured, although it is possible patients had admissions to hospitals outside of the local area. Mortality data were accessed from the national NHS registry to ensure accuracy. Only if patients had died outside of the UK and their GP had not been informed would these data have been unavailable.

It is unknown whether GP referrals to the memory clinic were prompted by concerns of the person with dementia, the carer or the GP and this may be a possible limitation to the study. It is also possible that people referred by the acute hospital had sought help previously from their GP but not been referred. If they had been referred to the clinic previously this would have been indicated on the database and their first referral only to the clinic would have been included in this analysis.

Conclusion

This study found that people diagnosed with dementia were more likely to be identified during an acute hospital admission and that people referred to the memory clinic by their GP were less likely to be diagnosed with dementia. There were significant differences in ethnicity and referral pathway, with those from BAME backgrounds more likely to be referred by their GP and people of white ethnicity more likely to be identified during an acute hospital admission. These findings may indicate differences in help seeking behaviour between different groups within a community, for which different approaches to identify undiagnosed dementia and encourage help seeking are needed. Memory clinic referrals that do not result in dementia diagnoses may be the result of improved awareness and prompt help seeking but may also indicate high levels of dementia worry and psychosocial stress within a community. Data on local memory clinic use can help service providers consider a more nuanced approach for different groups within a community when planning dementia and mental health service provision.

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Chapter 7: Phase Four Integration of Findings

The aim of the mixed-methods design in this study was for the systematic review, qualitative and quantitative phases to complement each other to provide a more complete understanding of why people may not seek help for a dementia diagnosis. In this chapter the aim of each phase of the study is highlighted, with a summary of how the aims were met. An overview of the process for integrating the three phases as detailed in Chapter Three is given followed by a discussion of the new integrated findings. This chapter is concluded with a consideration of the researcher's own positioning in the study and how their thoughts and experience may have been an influence throughout the study.

7.1 Summary of study phases

The systematic review in Chapter Four aimed to identify barriers and facilitators to help seeking for a diagnosis of dementia from the perspective of carers and people living with dementia. The review included 32 studies from a 30 year period across the globe and identified ten barrier themes: normalisation of symptoms, lack of perceived need, denial, preserving autonomy, lack of informal network support, lack of knowledge, problems accessing help, stigma and fear, unaware of changes and carer difficulties. Three facilitator themes were identified: recognising symptoms as a problem, support from the informal network and prior knowledge and contacts.

The qualitative phase in Chapter Five aimed to explore the experience of carers of people diagnosed with dementia during or following a hospital admission to understand why they had not sought help previously. The analysis of interviews with 12 carers of people diagnosed with dementia following an acute hospital admission, illustrated how carers created a 'bubble of normalisation' around themselves and the person living with dementia. The bubble was used to construct explanations that rejected a label of dementia and protected the person from a loss of independence, discrimination, and prejudice. There were missed opportunities to initiate the help seeking process as they encountered health care professionals and carers were fearful of talking about dementia. The diagnosis burst their bubble and left many feeling unsupported, still unable to talk about dementia and whilst the diagnosis confirmed suspicions for some, others questioned the value of the diagnosis.

The quantitative phase of the study in Chapter Six aimed to examine the characteristics of people referred to a memory clinic by their GP in contrast to those people referred to the memory clinic via the acute hospital and to determine factors associated with receiving a diagnosis of dementia and survival following diagnosis. Analysis of 1830 referrals to a memory clinic revealed that people referred to the memory clinic by the acute hospital were significantly more likely to be older and of white ethnicity than people referred by their GP. People diagnosed with dementia following a referral from the acute hospital were more likely to have severe dementia, more likely to have died 12 months post referral and more likely to have had hospital admissions before and after referral. People referred by their GP were more likely to be diagnosed with cognitive impairment or be cognitively intact following their assessment.

7.2 Data integration

To facilitate integration of the data, the author used the Pillar Integration Process developed by Johnson et al (2019). In a process that Johnson et al (2019) describe as *listing*, findings from the first three phases were juxtaposed in a table. The barrier and facilitator themes from the systematic review were displayed in one column, the themes from the qualitative analysis in the next column and statistically significant findings related to the differences between referral sources from the quantitative analysis in the third column. Detail of the data that had contributed to the themes for the systematic review and qualitative phase were also included to ensure that, when comparing the data in later stages, any inferences made could be traced back to the original data. The data were then compared, contrasted and rearranged in a process Johnson et al (2019) called *matching* so that findings which confirmed each other, enhanced each other to give a greater understanding of the topic or diverged from each other could be displayed together in rows. The third stage of *checking* was then employed for quality purposes to ensure that the matching of data in each row was appropriate and if any gaps were identified, whether these could be matched to data from other phases (Johnson et al 2019). The final stage of the process – *pillar building*, aimed to develop integrated themes from the matched data, and these create a "meaningful narrative" of the integrated results (Johnson et al 2019:307). The matched data from each phase created five new integrated themes to be explored further in the next stage of abductive and retroductive reasoning. These themes were Fear of the label of dementia, Alternative explanations, Preserving autonomy, independence and the way of life, The potential of informal networks and, The role

of health care professionals. The integrated data are presented in table 7.1 and a narrative to describe the meaning derived from the integration follows.

Table 7.1 Integrated findings			
Systematic Review themes and data	**Qualitative phase themes and data**	**Quantitative phase data**	**Integrated Theme**
Denial (barrier)- carer and PLWD unable to face possibility of dementia, denial and covering up of problems **Stigma and Fear** (barrier)- Negative attitudes & experiences, fear for how the PLWD would be treated after diagnosis, poor prognosis **Carer difficulties** (barrier) - carer worried about impact of diagnosis on themselves e.g. taking on carer role, fear of developing dementia **Lack of knowledge** (barrier) - lack of knowledge and awareness of signs and symptoms **Prior knowledge and contacts** (facilitator)- Working in health services, hospital connections, family	**Explaining to normalise** - Carers consider dementia but seek explanations to reject this **Fear of talking about dementia** - PLWD dismissed carer concerns, carer fear of PLWD reaction & damage to the relationship **To protect and preserve -** Use normalisation to stave off fear of the future and label of dementia, carer denial and fear of prejudice & discrimination **Still not talking –** diagnosis not disclosed to PLWD, carers fear of talking about diagnosis and reaction of PLWD **Diagnosis: bursting the bubble** – label of dementia changes everything	No data	**Fear of the label of dementia** - Awareness of the symptoms of dementia leads to fear of the stigma implied by a label of dementia. This prevents help seeking and results in a normalisation of symptoms and reluctance to talk about dementia both before and after diagnosis

history of dementia, knowledge from media sources			
Normalisation of symptoms (barrier) - Attributed symptoms to aging, stress, physical and psychological health problems, stressful life events **Carer difficulties** (barrier) - focused on managing physical health of PLWD **Lack of perceived need** (barrier) - Changes not problematic, not serious, providing practical help to support PLWD, nothing can be done **Unaware of changes** (barrier) - PLWD lives alone or at a distance, carer too close to the PLWD to notice changes **Recognising symptoms as a problem** (facilitator)- Gradual worsening of symptoms, key incident/ concern,	**Explaining to normalise** - Most carers recognise changes and attribute to ageing, physical or mental health problems. **To protect and preserve -** put practical measures in place to support PLWD	Increasing age associated with dementia diagnosis and older people more likely to be referred by acute hospital Acute hospital referrals had more hospital admissions pre and post diagnosis and more likely to have died at 12 months, people with three hospital admissions in 12 months pre-referral less likely to receive diagnosis Acute hospital referrals more likely to receive dementia diagnosis and have severe dementia at the time of diagnosis than GP referrals, people	**Alternative explanations** – alternative explanations are easy to find when the PLWD is older and has comorbid health problems. As symptoms worsen carers focus on managing these rather than seeking help.

normalisations failed, others recognised problem		with AD more likely to have survived at 12 months post referral	
Preserving autonomy (barrier) - Concerned diagnosis would undermine autonomy, respecting PLWD wishes not to seek help, respecting their independence, difficulty discussing symptoms **Stigma and Fear** (barrier)- Negative attitudes & experiences, fear for how the PLWD would be treated after diagnosis **Carer difficulties** (barrier) - carer worried about impact of the diagnosis on themselves, e.g. taking on carer role, having to make life-changing decisions	**To protect and preserve -** respect PLWD wish for independence, creating a bubble to protect way of life **Fear of talking about dementia** - carer fear of PLWD reaction & damage to relationship **Paying the price** – carers try to preserve independence post diagnosis but this has consequences for their relationship with PLWD as they become increasingly task focused	No data	**Preserving autonomy, independence, and the way of life** – the desire to maintain independence, autonomy, and the way of life for the PLWD and carer overrides any benefit anticipated from seeking help

Lack of informal network support (barrier) - Informal network disagreed over cause, seriousness of symptoms or the need to seek help **Support from informal network** (facilitator)- Informal network provide legitimacy, support & encouragement to seek help **Unaware of changes** (barrier) - PLWD lives alone or at a distance, carer too close to the PLWD to notice changes	**Explaining to normalise** – Informal network contribute to carer attributions to aging, physical or mental health problems. **To protect and preserve –** informal network support carer to create a bubble to protect the way of life by putting practical measures in place,	Older people more likely to be referred by acute hospital People of white ethnicity more likely to be referred by acute hospital and less likely to have survived 12 months post referral	**The potential of informal networks** – informal networks have the potential to both prevent and facilitate help seeking.
Problems accessing help (barrier) - Not knowing where to seek help, lack of insurance, immigration issues, language barriers **Recognising symptoms as a problem** (facilitator)- Gradual worsening of symptoms, key incident/ concern,	**Contact with Health professionals** – physical health problems dominated contacts, PLWD often attended appointments alone, ambiguity as to who should raise concern, HCP stigma, fragmented system	Acute hospital referrals had more hospital admissions pre and post diagnosis and more likely to have died at 12 months	**The role of health care professionals** – contact with health professionals does not necessarily result in diagnosis and carers may still need to initiate the help seeking process

normalisations failed, others recognised problem **Prior knowledge and contacts** (facilitator)- Working in health services, hospital connections, family history of dementia, knowledge from media sources **Support from informal network** (facilitator)- Informal network provide legitimacy, support & encouragement to seek help **Stigma and Fear** (barrier)- Negative attitudes & experiences, fear for how the PLWD would be treated after diagnosis, poor prognosis	**Diagnosis: bursting the bubble** – carers take the opportunity to seek help **Still not talking –** diagnosis not disclosed to PLWD **The doors close** – carers feel unsupported, compare diagnosis to other conditions and support they feel they should receive, question value of diagnosis		

7.2.1 Fear of the label of dementia

In the qualitative phase most carers considered the possibility of dementia and had some knowledge and awareness of the symptoms, including previous family experience or from working in health services. This finding partly diverges from those arising from the systematic review where a lack of knowledge was a barrier for some and having prior experience or knowledge could act as a facilitator to help seeking. Fear of the label of dementia and what this meant for the person living with dementia and the carer was evident in the qualitative phase and this was confirmed in themes from the systematic review. The themes of stigma and fear and carer difficulties in the systematic review help to confirm and enhance the findings as to the likely reasons why carers feared the label of dementia. As a result, both carers and the person living with dementia are reluctant to talk about dementia. This first integrated theme suggests that awareness of the symptoms of dementia can lead to fear of the stigma implied by a label of dementia. This prevents help seeking and results in a normalisation of symptoms and reluctance to talk about dementia both before and after diagnosis.

7.2.2 Alternative explanations

Carers in the qualitative phase of the study attributed the changes they were seeing to aging, physical and mental health problems. This finding was confirmed by themes in the systematic review and enhanced by data from the quantitative phase as people referred by the acute hospital were older than those referred by their GP. Findings of the qualitative phase diverged from barriers in the systematic review, as carers were aware of changes taking place and although they recognised that these were gradually worsening, this was not enough to prompt them to seek help. Findings of the quantitative phase that people diagnosed following referral from the acute hospital had more severe dementia, again diverged from the systematic review findings, suggesting that worsening problems were not enough to prompt help seeking in this group. In the regression analysis people with Alzheimer's disease were more likely to have survived 12 months post referral, possibly suggesting they had been diagnosed at an earlier stage of the disease process. As memory problems are a common early symptom of Alzheimer's disease, these symptoms may be more likely to prompt help seeking, whereas other non-cognitive symptoms associated with other types of dementia may be easier to attribute to other causes. Findings of the qualitative phase diverged from this as even though carers were aware of memory problems, they did not seek help. The physical health problems

of the person living with dementia were often the main focus for carers both in the systematic review and the qualitative phase. Findings of the quantitative phase of this study enhance this as people referred from the acute hospital were more likely to have had hospital admissions before and after diagnosis. The finding in the regression analysis that people with three or more admissions to hospital in the 12 months pre-referral were less likely to receive a diagnosis of dementia emphasises the close links between physical and cognitive health problems, as health care professionals were referring people with multiple hospital admissions to the memory clinic. This second integrated theme suggests that alternative explanations are easy to find when the person living with dementia is older and has comorbid health problems. As symptoms worsen carers focus on managing these rather than seeking help.

7.2.3 Preserving autonomy, independence, and the way of life

Respecting the autonomy of the person living with dementia and striving to maintain their independence was a key reason for creating the bubble of normalisation for carers in the qualitative phase of this study. This finding was confirmed in the preserving autonomy theme from the systematic review. The qualitative phase theme of paying the price enhanced understanding of this, as preserving independence became more difficult post diagnosis and some carers fears, such as institutionalisation, were realised. Protecting the way of life for the person living with dementia and carer was also a function of the bubble of normalisation and this was confirmed by the carer difficulties theme in the systematic review. The theme stigma and fear enhance understanding of this as carers do not anticipate positive outcomes from a diagnosis, and again this results in a fear of talking about dementia. This third integrated theme suggests that the desire to maintain independence, autonomy and the way of life for the person living with dementia and carer overrides any benefit anticipated from seeking help.

7.2.4 The potential of informal networks

The informal network did not feature strongly in the qualitative phase but where they did, they contributed to the carer's attribution of symptoms to age or other health problems and supported the carer to put in place practical measures to maintain the person living with dementia's way of life. This finding diverged from those arising from the systematic review where the informal network was both an important barrier and facilitator to the carer seeking help. The theme unaware of changes in the systematic review supports findings of the quantitative phase that people referred by the acute hospital were older and more likely to be

of white ethnicity. This is less likely to be associated with ethnicity per se but with the social position of this ethnic group in the sample of the study. Data from other sources suggests that older people of white ethnicity are more likely to be socially excluded and have reduced social networks in the community of the study sample. The findings of the regression analysis that people of white ethnicity were less likely to have survived 12 months post referral suggests they were diagnosed at a later stage in the disease process and that reduced social networks in this group may have contributed to later help seeking. This fourth integrated theme suggests that informal networks have the potential to both prevent and facilitate help seeking.

7.2.5 The role of health care professionals

In the qualitative phase, contact with healthcare professionals was a missed opportunity to seek help. This is enhanced by the quantitative findings that people referred from the acute hospital had more hospital admissions before diagnosis. But this diverged from facilitator themes in the systematic review where healthcare professionals recognised problems or connections to health services facilitated help seeking. Carers in the qualitative phase did not have the same problems accessing help as those represented in the systematic review, but there was ambiguity as to whose responsibility initiating help seeking was – the carer or the health care professional. Whereas the informal network legitimised help seeking in the systematic review, the hospital admission gave some carers legitimacy to seek help in the qualitative phase. Stigma experienced by carers and people living with dementia in the systematic review may help to enhance understanding of health care professional actions and the lack of support perceived by carers following diagnosis. This final integrated theme suggests contact with health professionals does not necessarily result in diagnosis and carers may still need to initiate the help seeking process.

7.3 Summary

The integration of data from the systematic review, qualitative and quantitative phases resulted in five integrated themes: Fear of the label of dementia, alternative explanations, preserving autonomy, independence and the way of life, the potential of informal networks and the role of health care professionals. The next stage of a critical realist explanatory research study is abductive and retroductive reasoning. Chapter Eight will use abduction and retroduction to explore the five integrated themes and propose a model of the underlying causal mechanisms preventing help seeking for a dementia diagnosis.

Chapter 8 Identification and discussion of the causal mechanisms preventing help seeking

The study aimed to understand why people may not seek help for a diagnosis of dementia. Critical realist research seeks to identify the causal mechanisms which generate events and specify how different causal mechanisms interact and the circumstances under which they interact to produce events (Danermark et al 2019). In Danermark et al's (2019) stages of critical realist explanatory research outlined in Chapter Three, the identification of mechanisms takes place through abductive and retroductive reasoning. This chapter begins with a brief summary of what is meant by these forms of reasoning and how they have been applied in this thesis. Abductive and retroductive reasoning were employed using relevant theory to explain the integrated themes derived in Chapter Seven and propose the causal mechanisms that prevent help seeking for a diagnosis of dementia.

8.1 Abductive reasoning

Abduction is described as a process of re-description and recontextualization (Danermark et al 2019). In this process, empirical findings are described, interpreted, and explained within the frame of existing theories or concepts. From a critical realist perspective, this process facilitates a move from the empirical domain of reality (people's experiences of events) to understanding what actually happened (in the actual domain of reality) and to start the identification of structures and mechanisms in the real domain of reality that caused these events to happen. This approach allows both a deeper understanding of the population under study and the ability to determine theories which may explain underlying structures and powers of mechanisms that can be tested in future research.

8.2 Retroductive reasoning

The process of retroduction follows abduction, although the two processes are closely aligned. The outcome of critical realist research should be the "identification of the causal mechanisms generating events, and the examination of how different mechanisms cooperate and, under specific circumstances, contribute to the production of concrete events and processes" (Danermark et al 2019:129). Using the theories or concepts identified in the abductive reasoning, retroduction seeks to achieve this and in the case of this thesis, identify the mechanisms that prevent help seeking for a diagnosis of dementia and the context or other

mechanisms that may interact to influence the outcome (Danermark et al 2019). There is no universal method for undertaking retroduction, but counterfactual thinking is considered an essential part of the process and is applied in this chapter (Danermark et al 2019). Counterfactual thinking involves, "understanding what something is in relation to what it is not" (Danermark et al, 2019:122). By considering what mechanisms and contexts are required to facilitate help seeking for a diagnosis of dementia, we can postulate what mechanisms and contexts are required to prevent it. The product of the retroductive process is a proposition of what must exist to prevent help seeking for a dementia diagnosis. Although the CMO (context mechanism outcome) configuration is most commonly used in realist evaluation rather than detached explanatory realist studies such as this one, Eastwood et al (2016) used a graphical representation to illustrate the proposition that results from abductive and retroductive reasoning in their study and this is used to represent the propositions made in this thesis (Figure 8.1).

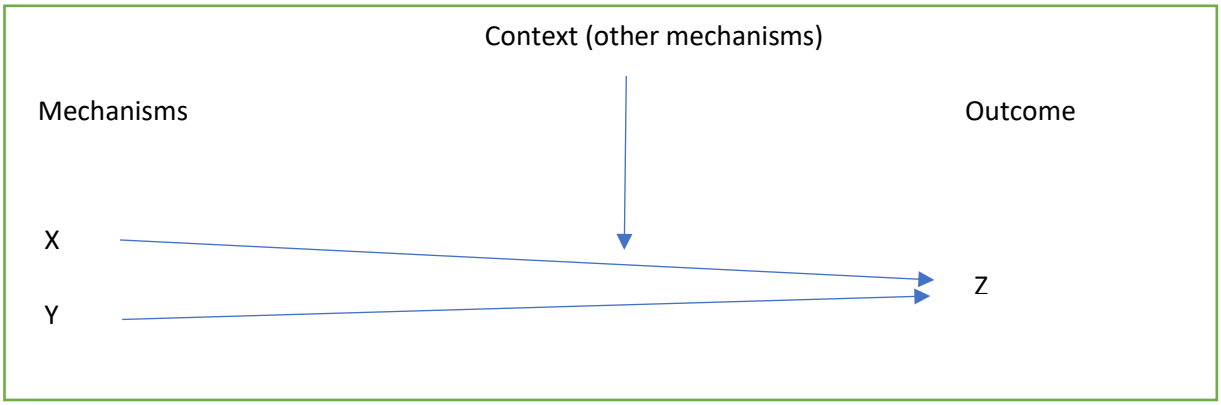

Figure 8.1 Graphical representation of the proposition resulting from abductive and retroductive reasoning (Eastwood et al 2016).

8.3 Application of abductive and retroductive reasoning in this thesis

Chapter Three explained that mechanisms exist at different strata of reality e.g. physical, chemical, biological, psychological, social, economic, organisational etc. It is recommended that studies focus on the mechanisms within the strata to which a research problem belongs, and it is beyond the scope of this thesis to discuss mechanisms that prevent help seeking for a dementia diagnosis at multiple levels of reality, so the focus here will be on the mechanisms within the social stratum (Danermark et al 2019). Blom and Moren (2010) describe social

mechanisms existing at three analytical levels with relationships between agents and structures at each level (Table 8.1).

Table 8.1 Three levels of social mechanisms (Adapted from Blom & Moren 2010)

Social mechanisms consist of causes, motives, considerations, and choices of individual agents mediated at three levels	**Micro-social mechanisms** are mediated by micro-social interaction at an individual level (dyads or smaller groups) and social and material structures such role expectations
	Meso-social mechanisms are mediated by meso-social interaction (within and between groups, networks, and organisations) and social and material structures such as routines and bodies of regulation
	Macro – social mechanisms are mediated by macro-social interaction (social interplay within and between societies) and social and material structures such as health care systems and political parties

In this chapter theories and concepts will be used to re-describe and recontextualise the integrated themes from Chapter Seven in the process of abduction. In reviewing the integrated themes there were a broad range of possibilities to explore through abductive reasoning. The researcher felt that there were elements of the integrated themes which overlapped and could possibly be explained by similar concepts and theories.

Theories related to stigma were appropriate to discuss the theme *Fear of the label of dementia* and *Alternative explanations.* The researcher looked to theories of stigma that had been previously applied to dementia – Attribution theory (Corrigan 2000) and Modified Labelling Theory (Link et al 1989) – in order to explain these integrated themes.

The theme *Preserving autonomy, independence and the way of life* could also be partially explained by stigma, but the researcher felt this was an important aspect to explore separately and the actions of carers in response to a threat to autonomy and independence was chosen as the area for discussion. Ageism and the social imaginary of the fourth age were chosen as concepts which could explain why threats to autonomy and independence were feared by

carers and PLWD. To explain the carer response to these threats the researcher briefly considers the usefulness of theories of coping and then chose four qualitative studies involving carers of PLWD that sought to conceptualise how carers respond to threats to independence and autonomy across their caregiving career, to shed light on the pre-diagnosis period.

The integrated theme, *The potential of informal networks* highlighted the possibility that informal networks had the potential to prevent and facilitate help seeking, so this was considered in relation to the role of social networks in help seeking. Despite there being a broad body of research related to social networks and dementia, this is mainly atheoretical. After considering different theories related to social networks, the researcher chose to use the Network Episode Model (Pescosolido and Boyer 2010) to explain the integrated findings. Although developed from the perspective of mental illness, the model specifically considers the role of the social network in help seeking and related work by Pescosolido on health discussions also made this theory a good fit for the integrated findings.

The role of health care professionals as the final integrated theme was felt to cut across concepts of stigma, the carer response to a threat to independence and autonomy and the role of social networks, so was considered alongside the other themes in the discussion.

The premises of each theory or concept are described briefly, the extent to which they are supported in existing dementia research and then how they relate to the study findings and integrated themes. A proposition of the mechanism and its context is then made. Not all theories that form the basis of a proposition are equally likely to provide a full explanation, so the advantages and limitations of a theory must also be explored.

The theories and concepts described above to explain these three broad areas - stigma, the carer response to a threat to independence and autonomy and the role of the social network are now considered.

8.4 Stigma

The concept of stigma emerged explicitly and implicitly in both the systematic review and qualitative phase and is the first social structure to be considered as underpinning the prevention of help seeking for a diagnosis of dementia.

Stigma is a phenomenon embedded in social relationships and one which 'is defined in and enacted through social interaction' at the micro, meso and macro level (Pescosolido et al 2008:432). Goffman defined stigma as a 'deeply discrediting' attribute that can reduce 'a

whole and usual person to a tainted, discounted one' (Goffman, 1963:12-13). Since Goffman's seminal work on stigma, the concept has been widely discussed and re-conceptualised, particularly in relation to mental illness (Link and Phelan 2009). Two widely used conceptualisations in the literature related to stigma and mental illness are those of Corrigan and Kleinlein (2005) and Link and Phelan (2001). Link and Phelan (2001) describe stigma as existing when four interrelated components converge,

> "In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics – to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them". In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes." (p367)

Importantly they assert that stigma can only exist when there is a social, economic, or political power imbalance between those labelled as different and those who are not. Corrigan and Kleinlein (2005) conceptualise stigma as stereotypes, prejudice, and discrimination. Stereotypes are "general beliefs about the characteristics, attributes and behaviours of people who are categorizable as a member of particular social group" and these beliefs are culturally defined and learned from childhood (Corrigan and Shapiro 2011:3). Prejudice is the generalised attitude held about a group, such as fear of people with mental illness, and discrimination is the behavioural consequence of prejudice. The presence of stereotypes does not necessarily lead to prejudice and discrimination, as people may be aware of stereotypes but not endorse them. These two conceptualisations of stigma are related to two theoretical concepts that have been widely used in stigma related to mental illness: Attribution theory which has a focus on public stigma and Modified Labelling theory which has a focus on self-stigma (Rusch et al 2005). These two theories are used to explore the stigma associated with preventing help seeking for a diagnosis of dementia in this study. This is preceded with a brief overview of the types of stigma and the extent to which they are prevalent in dementia.

8.4.1 Stigma and Dementia

Stigma is a complex phenomenon and can be classified into different types (Table 8.2).

Table 8.2 Types of Stigma

Public stigma – the endorsement of stereotypes by the public resulting in discrimination (Jones and Corrigan 2014). Can also be referred to as enacted stigma.
Self-Stigma - an individual's internalisation of public stereotypes. It involves the individual being aware of the public stereotypes, agreeing with these stereotypes and applying one or more of them to themselves resulting in self-discrimination (Jones and Corrigan 2014). Can also be referred to as internalised stigma
Structural stigma - rules, policies, or procedures that either intentionally or unintentionally discriminate against stigmatised individuals (Jones and Corrigan 2014)
Courtesy stigma - the extension of stigma from an individual to those close to them (Moses 2014). Can also be referred to as family stigma, associative/ affiliative stigma.

It is well recognised that dementia related stigma exists, although the evidence base for this is less well established than for stigma in other areas, such as mental illness. A global survey of people living with dementia and carers for the 2019 Alzheimer's Disease International report (Alzheimer's Disease International, 2019), found that people living with dementia felt treated unfairly across many domains of life including their social life, housing, within relationships and families and within health care. Some people felt their rights and responsibilities were taken away unfairly, their opinions not taken seriously, they lost friends and in some regions of the world their dementia was mocked. As a result, some people living with dementia and some carers concealed their diagnosis from others. Three reviews of dementia related stigma research have been conducted in recent years (Werner 2014, Herrmann et al 2018, Nguyen and Li 2020). Herrmann et al (2018) reviewed a decade of global research on dementia related stigma to determine stigmatising attitudes in various subgroups of the population, the use of stigma assessment tools and approaches to manage stigma. Nguyen and Li (2020) aimed to determine how public stigma towards people living with dementia and the self-stigma of people living with dementia and their families manifested itself and the factors associated with it. Werner (2014) reviewed studies of dementia related stigma between 1990 and 2012, paying particular attention to the concepts, frameworks and methods used. Findings of the three reviews are now summarised.

Studies of public stigma reported beliefs about dementia including dangerousness, that dementia results in a loss of self-esteem, lower competence and poor personal appearance which provoked thoughts related to death, fear, anxiety, shame and disgust amongst the general public (Nguyen and Li 2020, Werner 2014). Although more studies reported negative emotions, positive and neutral emotions such as pity, sympathy and empathy were also

reported and when compared to other illnesses there were lower levels of stigma towards dementia (Nguyen and Li 2020, Werner 2014). Lay public discriminatory behaviour towards people living with dementia is most often reported as social distancing or avoidance, but discrimination from health professionals hindering diagnosis, help seeking and access to services was also frequently reported (Herrmann et al 2018, Nguyen and Li 2020). Positive behaviours such as lay public willingness to help people with dementia were also reported (Nguyen and Li 2020). Increased severity of dementia and the more dangerous people living with dementia were considered to be, were associated with greater stigma however, knowing someone with dementia was associated with lower stigma (Herrmann et al 2018, Nguyen and Li 2020). Females, older people, and those with higher education levels expressed less stigma (Herrmann et al 2018, Nguyen and Li 2020). Less knowledge of dementia and some cultural interpretations of dementia may increase stigma (Herrmann et al 2018). Only one carer interviewed in the qualitative phase of this study reported experiencing public stigma towards the person they cared for and this was manifested as social distancing or avoidance, as fellow residents in sheltered accommodation distanced themselves from the person living with dementia. Carers in this study were more likely to express feelings of self-stigma.

There were fewer studies of self-stigma in the three reviews and these included the stigma felt by carers. In these studies people living with dementia and carers described perceived public stigma from seeing negative images in the media resulting in feelings of low self-esteem, shame, fear, anxiety, frustration, and loss of confidence (Nguyen and Li 2020, Werner 2014). The consequences of this were denying or concealing the diagnosis, social withdrawal and reduced help seeking (Nguyen and Li 2020, Werner 2014). Very few studies included structural stigma, but those that did reported delayed diagnosis and treatment, differential access to services and increased institutionalisation (Werner 2014). In the qualitative phase of this study carers had negative views of dementia, although it was not clear where these had come from. One carer expressed the view that they would be selective in who they revealed the diagnosis to, and by not talking about dementia carers were often denying or concealing the diagnosis from the person they cared for. It is possible that structural stigma may have led to the delay in diagnosis for some people living with dementia in the qualitative phase, as many were in regular contact with health services in the years before diagnosis. Carers in the qualitative phase of this study also faced difficulties accessing support post diagnosis and structural stigma has been linked to the level funding for dementia care and support (Alzheimer's Disease International 2019).

Dementia related stigma research originates from a limited number of countries and is predominately based on quantitative studies of public stigma using vignettes (Nguyen and Li 2020). There is also variability in the definitions and concepts of stigma that are studied, and the research is largely atheoretical (Werner 2014). Consequently, there is still much to understand about the causes and consequences of stigma for people living with dementia and their carers. Much of the research on dementia related stigma is not based within a theoretical framework, but two theoretical concepts - Attribution theory and Modified Labelling Theory have been used to explore stigma in dementia. The extent to which these two theories can help explain how stigma can prevent carers from seeking help for a diagnosis of dementia is now explored.

8.4.2 Attribution Theory

Attribution theory starts with the assumption that people need to understand the cause of everyday events and has been widely used as an approach to understand stigma related to people with mental illness (Corrigan 2000). It is proposed that when presented with symptom related behaviour or a label, people make a causal attribution that subsequently influences their emotional response and behavioural reaction. If their causal attribution is a stereotype, then their emotional response may be prejudice and their behavioural reaction discrimination (Werner 2014). Causal attributions related to two attitudes – stability of causes and controllability of causes, have been found to influence emotional and behavioural responses (Corrigan 2000). Stability relates to the extent to which a person is likely to recover from a perceived illness and controllability relates to the extent to which a person has responsibility for contracting or developing the disease (onset controllability) and the extent to which they are trying to overcome or cope with the disease (offset controllability). Attributions of stability do not affect emotional and behavioural responses, but they do impact on the weight given to the causal attribution. For example, a causal attribution that is stable and unchanging, such as a diagnosis of dementia that has no cure and a terminal prognosis, is given more weight (and possibly greater stigma) than a diagnosis of a curable disease or one in which there is hope to improve. Attribution theory applied to the stigma of mental illness asserts that people who are judged to have more control or responsibility for their illness are more likely to be responded to angrily with punishing behaviour and those judged to have less control or responsibility for their illness are more likely to be responded to with pity and helping behaviour (Corrigan 2000).

There are some elements of attribution theory that can be used to explain how stigma prevented help seeking for a diagnosis of dementia for carers in the qualitative phase of this study. Carers made causal attributions to the changes they were seeing in the person they cared for and many thought the cause of these changes could be dementia. For many carers this causal attribution of dementia was associated with negative stereotypes, particularly a loss of independence and autonomy, but this resulted in positive emotional reactions from carers of compassion and pity and led to increased caregiving and practical support. This could be related to the fact that carers did not see the person as having any responsibility for developing the disease (onset controllability) and many carers valued the efforts made by the person to remain as independent as possible (offset controllability). Positive emotional reactions towards people living with dementia have been found in studies of public stigma using vignettes where Alzheimer's disease was associated with less responsibility, greater sympathy, and a greater willingness to help compared to major depression (Wadley and Haley 2001). People with Alzheimer's disease were accorded higher levels of pity than people with depression, alcohol dependence and nicotine dependence in another study, although people with Alzheimer's disease were associated with lower perceptions of recovery and benefit from counselling, (Kubiak et al 2011).

However, in the qualitative phase of this study alongside carer's positive emotional responses were negative emotional reactions of fear. These prevented carers talking about dementia and led to denial and the seeking of alternative explanations. It is possible that the attribution of causal stability, in this case the poor prognosis associated with dementia, had a stronger impact on the emotional and behavioural reactions of carers in this study than the controllability of the cause did. So, although carers did provide increased support to the person living with dementia, they distanced themselves from the 'real problem' by not discussing it or pursuing help seeking opportunities. Increased severity of the disease has been associated with increased discriminatory behaviour in studies exploring stigma with carers of people living with dementia (Werner 2010, Werner et al 2012). In a qualitative study of 10 family carers, the causal attributions of carers which led to their own discriminatory behaviour towards the person living with dementia were the severity of the disease, the functional status of the person and their physical appearance or aesthetics (Werner 2010). For some, these attributions provoked emotional reactions of shame, embarrassment and disgust that led to the concealment of the diagnosis and the person living with dementia and reduced caregiving. For others, they provoked positive emotions of compassion, sorrow and guilt, which led to increased involvement in caring. In addition to their own stigma carers were aware of the

stigma of others, where the same causal attributions resulted in fear and disgust or pity leading to other people avoiding the person living with dementia (fear and disgust) or increasing social contact (pity).

Research using attribution theory to explain dementia related stigma is limited with several studies carried out by the same research team in Israel and most studies using lay public samples with vignettes which may not reflect people's actual behaviour if personally faced with the situation. However, they do provide support to the theory that causal attributions of dementia lead to emotional reactions and behavioural responses, including positive emotional reactions such as sympathy and compassion. This response was the case for carers in this study, although the research described above suggests increasing severity of the disease may lead to increased discriminatory behaviour and for carers in this study it led to a search for alternative explanations and an avoidance of discussion about dementia. Attribution theory can help to understand how causal attributions lead to discriminatory behaviour, but it does not help our understanding of the origins of the causal attributions carers make and why they provoke the emotional reactions, such as fear, that they do for some carers and not others. The next section considers another theoretical approach to stigma, Modified Labelling theory, which may help to explain this.

8.4.3 Modified Labelling theory

Modified Labelling theory, in the context of stigma related to mental illness, was developed by Link et al (1989) and is described in five steps. In step one, over time individual beliefs about mental illness and the extent to which people with mental illness will be devalued and discriminated against within a community are developed. When a person receives a label of a mental health problem in step two their beliefs about the devaluation and discrimination of people who are mentally ill become personally relevant. An individual's response to their stigmatizing status in step three can be secrecy or concealing the diagnosis, withdrawal or limiting of social contact or the education of others to change their views and reduce discrimination. Negative consequences of the stigma process may arise in step four from the beliefs and attitudes of others developed in step one or from the individual's responses to the label in step three. These negative consequences can lead to social or psychological

vulnerabilities in step five, such as low self-esteem, reduced social network and unemployment, that increase the risk of further or prolonged mental illness.

The theory proposes a link between the public stigma that develops in step one and the individual's response in step three, as the negative beliefs of others are internalised and have a harmful impact on an individual's sense of self, leading to self-stigma. Subsequent research into stigma and mental illness has shown that higher levels of public stigma result in higher levels of self-stigma and that this has a negative influence on help seeking (Vogel et al 2013). Consequently, it is an appropriate theory to consider in relation to help seeking for a dementia diagnosis.

If people living with dementia and carers are aware of negative beliefs about dementia in the society and feel that they will be discriminated against or devalued as a result of diagnosis, then they may not seek help for a diagnosis, in order to avoid reaching step two and receiving a label of dementia. In the qualitative phase of this study, the anticipated label of dementia had significant personal relevance for carers, and they sought alternative explanations to avoid the label of dementia, creating a bubble of normalisation to protect themselves and the person living with dementia from the diagnosis. The presence of symptoms, which they recognised as possibly being dementia, was enough for them to respond to any negative beliefs about dementia they held.

Studying the effect of a dementia label on the presence of stigma has been the subject of a limited number of studies. In one vignette-based study the level of stigma did not vary significantly between participants exposed to vignettes with the diagnostic label of dementia and those exposed to vignettes without the label (Cheng et al 2011). Wadley and Haley (2001) found that willingness to help was associated with the label of Alzheimer's Disease compared to the same vignette without a diagnostic label, suggesting that the label reduced stigma. A finding supported in another study where respondents to a vignette labelled with Alzheimer's disease expressed less negative aesthetic judgements than respondents to the same vignette with a traumatic brain injury label or no label (Johnson et al 2015). However, vignettes labelled as having a poor prognosis (no treatment and will worsen) were significantly associated with greater stigma. The findings of these studies contrast with the literature on stigma and mental illness where labelling has led to more discriminatory behaviour (Angermeyer and Dietrich 2006).

It is possible that the stigma attached to the label of dementia may be related to the poor prognosis associated with dementia, rather than the disease label itself (Johnson et al 2015)

and this would support findings of attribution theory studies where severity of the disease was related to more discriminatory behaviour (Werner 2005, Werner 2010, Werner et al 2012). In the qualitative phase of this study the label of dementia held various meanings for carers. It represented an inevitable decline, that threatened the person living with dementia's autonomy, independence, and their way of life and this was the driving force behind the carers desire to avoid a diagnosis. But the label also had the power to change the person living with dementia in the eyes of the carer and change the way the carer saw themselves and their way of life.

Studies involving people with living dementia and carers have more strongly supported the impact of a label of dementia than studies involving lay public samples. The label of dementia and its association with mental illness was a source of stigma for Chinese American and Vietnamese American people living with dementia and carers, some of whom chose to normalise symptoms in order to avoid the diagnostic label (Hinton et al 2000, Lui et al 2008). A study of staff, residents and their families from assisted living and residential care settings found that negative reactions to the label of cognitive impairment or dementia were common amongst residents, resulting in social distancing from those with a diagnosis and denial of possible symptoms within residents themselves (Dobbs et al 2008). Care professionals in another study describe how people living with dementia distinguished themselves from other people whose dementia was more severe and how family members denied the diagnosis, particularly when they feared being judged by others (Walmsley and McCormack 2016). Other people living with dementia and carers have spoken about how they feared the label of diagnosis would alter the reactions of others, so kept the diagnosis to themselves or within family and although some people living with dementia expressed positive attitudes towards living with dementia it was also clear that they had internalised negative stereotypes about dementia which influenced whether they shared their diagnosis (O'Sullivan et al 2014). Experiences of some of the carers in the qualitative phase of this study resonate with these findings, as the person they cared for experienced discrimination from other people or carers feared the person living with dementia would be discriminated against.

Although research that directly considers the meaning of the label of dementia and its impact on stigma is limited, there has been concern over the pejorative connotations of the literal translation of the term dementia (meaning 'no- mind' or 'out of one's mind') and its influence on stigma. This was one of the reasons the term dementia was replaced in the DSM-5 in 2013 with Major Neurocognitive Disorder (Sachdev et al 2014). Following a successful campaign, a new term for dementia is now used in Japan (Miyamoto et al 2011), whilst campaigns to

replace variations of Chinese terms for dementia in East Asian countries continue (Chui et al 2014).

Research explaining dementia related stigma using Modified Labelling theory is limited and variable. What is interesting however is that vignette studies with lay public samples do not support that a label of dementia leads to stigma, whereas in qualitative studies with older people, people living with dementia and their carers the label is related to stigma. The findings of the qualitative phase of this study also support this. This lends support to step two of Link et al's (1989) theory that the personal relevance of the label and an individual's subsequent response lead to the experience of stigma. This appeared to be the case for the carers in this study and self-stigma and label avoidance have both been associated with reduced help seeking in mental illness (Schnyder et al 2017, Horsfield et al 2020).

8.4.4 The contribution of stigma theory

Considering both the research using attribution theory and modified labelling theory together, the poor prognosis associated with a label of dementia seems a likely underlying cause of the stigma associated with dementia for carers in this study. Carers had negative beliefs about what having dementia means, for example, a poor prognosis with a loss of independence and autonomy. These beliefs had been internalised and became personally relevant to the carer when they suspected their loved one might have dementia. This perception provoked both positive and negative emotions that resulted in increased caregiving and support but a distancing from the 'real' problem and avoidance of diagnosis.

Using counterfactual thinking as part of the retroductive reasoning process one should consider how this might apply to carers who **do** seek help for a diagnosis of dementia, to determine if stigma is a full explanation for how help seeking for a diagnosis is prevented. One could assume that those carers who do seek help, do not have negative internalised beliefs about dementia which become personally relevant when their loved ones develop signs of dementia. However, some of the qualitative studies reported here show that these negative stigmatising beliefs exist for people living with dementia and their carers post diagnosis, so cannot prevent help seeking for all (O'Sullivan et al 2014, Walmsley and McCormack 2016, Lui et al 2008, Werner et al 2010). It is possible that carers who sought help knew little about dementia or did not consider dementia a cause of the changes they were witnessing before they sought help. But it is also likely that other factors may be contributing to the prevention of help seeking.

There is some evidence that the poor prognosis of dementia may be a factor in determining whether health care professionals proactively discuss or initiate dementia assessment. In the integrated theme, the role of health care professionals, it was acknowledged that they may not always initiate assessment and in the qualitative phase there were many missed opportunities for health care professionals to initiate a conversation with the carer, either about their own concerns or to enquire about the carers concerns. Therapeutic nihilism is described as "an inappropriately pessimistic view of a patient's outcome" and their ability to benefit from treatment, depriving them of the chance to judge for themselves what an acceptable outcome would be (Hirschi et al 2017:1801). In the case of dementia diagnosis this is most often associated with a belief that because a cure or disease modifying therapy for dementia does not exist, there is no benefit to diagnosis and it may cause more harm than good (Koch and Iliffe 2010). Negative attitudes of primary care physicians regarding the benefits of an early diagnosis, prioritising physical health problems over dementia and concerns that increased dementia care would put an additional strain on overstretched health services, are all considered barriers to a timely diagnosis of dementia in primary care (Aminzadeh et al 2012, Koch and Iliffe 2010). Concern from primary care physicians that people living with dementia and their carers would be stigmatised has also been cited as a barrier to diagnosis (Koch and Iliffe 2010). Primary care and the GP are usually the first point of contact for people concerned about their memory and in the qualitative phase of this study people living with dementia were seeing their GP on a regular basis. Qualitative research with GPs in the UK demonstrated an awareness of dementia stigma in society and how this may deter people from seeking a diagnosis, but also revealed GP's own beliefs about a lack of reciprocity from people living with dementia in social interactions and to society in general, which the authors suggest has implications for a timely diagnosis (Gove et al 2016, Gove et al 2017). As the perspectives of the health care professionals involved in the care of people living with dementia in the qualitative phase of this study were not sought, an assumption that therapeutic nihilism underpinned any of the missed opportunities to initiate or discuss dementia assessment should not be made. But there is evidence that these negative attitudes exist, and therefore it should be considered as a possible factor preventing help seeking in this group of carers.

8.4.5 Proposition 1

It is now possible to make a proposition as to how the social phenomenon of stigma may prevent help seeking for a diagnosis of dementia. (Figure 8.2). It is proposed that stigma is a

necessary mechanism in preventing help seeking for a dementia diagnosis. This is in the context of carers having knowledge and awareness of dementia, but internalised negative beliefs about the poor prognosis of dementia and therapeutic nihilism on the part of health professionals involved in the care of the person living with dementia. The outcome of this is fear in the carer that results in normalisation of symptoms and seeking practical support to manage the care of the person living with dementia rather than seeking help for a diagnosis. Although the theories of attribution and labelling give some context as to how stigma prevents help seeking, further exploration of the specific threats resulting from stigma and other potential factors preventing help seeking is now required.

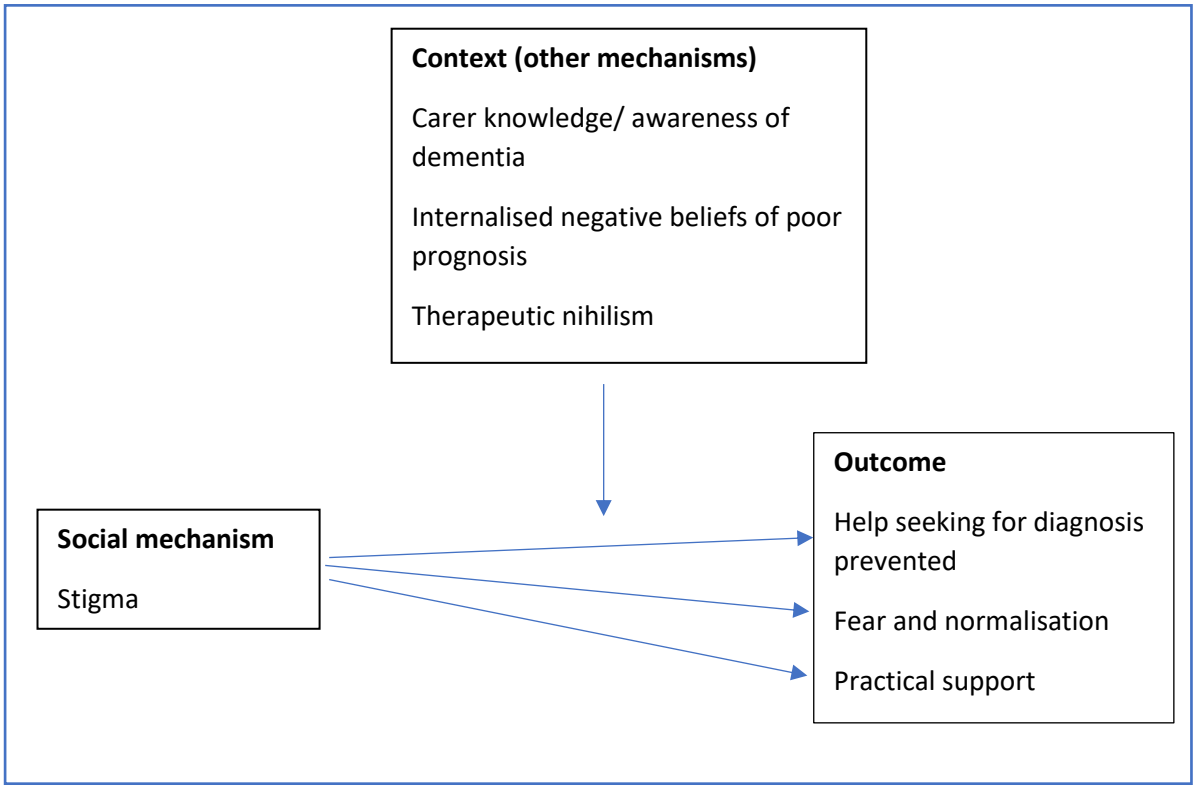

Figure 8.2 Proposition 1 Stigma

8.5 The threat to autonomy and independence - the carer response

The integrated theme *Preserving autonomy, independence and the way of life* reflected the way carers responded to the changes they were witnessing in their loved one in both the qualitative phase and systematic review. The need to protect appeared to override any benefit that might have been anticipated from seeking help. The concepts of autonomy and independence and how the carers response to a threat to these could prevent help seeking for a diagnosis of dementia is now explored.

The concepts of autonomy and independence are interlinked. Autonomy can be described as, "independent and effective functioning in a variety of life domains ranging from basic activities of daily living to expanded leisure activities and complex decision making" (Wahl 2015:181). Independence can be described as, "A sense or state of physical, psychological and spiritual autonomy, self-identity, self-respect, control and degree of functional capacity" (Phillips et al 2010:2). Although sometimes represented as a continuum from independence to dependence, with the two being mutually exclusive, it is recognised that the meaning of independence is culturally situated and subjective, and that independence can exist in the presence of dependence (Phillips et al 2010). Some of the meanings attributed to independence by older people in research can be summarised as,

> "being able to look after one-self and having a sense of self-reliance; preserving a sense of individuality, self-esteem, self-awareness and identity…; having the capacity and freedom to make decisions for oneself and remain autonomous; not feeling any sense of obligation or debt towards others; engaging in meaningful activities…through reciprocal exchanges or through a recognition of roles by others." (Phillips et al 2010:2)

A sense of self and identity is a strong component of the definitions and meanings attributed to independence, and dementia is often considered a threat to this sense of self (Sabat and Harré 1992). A biomedical model of dementia, in which it is portrayed primarily as a disease of "decline, decay and deficiency", tends to predominate the images of dementia that are most accessible to the general public (Innes and Manthorpe 2012:686, Bailey et al 2019). Although other explanatory models have a greater focus on the social and psychological experiences of people living with dementia and their carers, and the possibility of living well with dementia, they reside largely within research and policy and less within the popular media (Innes and

Manthorpe 2012). Negative images of dementia often combine with negative images of ageing, as the risk of developing dementia increases with age and for many people dementia is still considered a 'normal' part of ageing.

In the integrated theme of *Alternative explanations*, attributing changes to normal ageing was common amongst carers in the qualitative phase of this study and in the systematic review and could explain why people referred by the acute hospital in the quantitative phase were significantly older. Ageing stereotypes become embedded in individuals from childhood and may result in self-stereotypes as we enter old age (Scholl and Sabat 2008). This combination of ageism and negative images of dementia is often referred to as the double stigma experienced by older people living with dementia (Milne 2010b). Downs et al (2006b) also consider how models such as the biomedical models of dementia position older people as patients and their families as carers with an associated care burden. Any subsequent actions on the part of the person living with dementia are then attributed solely to their diagnosis and over time could lead to the person living with dementia being excluded from discussions and decisions by health professionals and carers through a process of malignant positioning (Sabat 2006). This could be seen to start at the time of diagnosis for people living with dementia in the qualitative phase of this study as many were not informed of their diagnosis and carers did not engage in discussions about the diagnosis with the person they cared for. It is these negative images, stereotypes and re-positioning of older people and people living with dementia in society that pose a threat to independence, autonomy and a sense of self and have led to dementia being regarded as the condition most feared by UK adults (Alzheimer's Research UK, 2018).

Adults caring for a parent with dementia, like the majority of carers in the qualitative phase of this study and in the systematic review, will not necessarily associate ageing stereotypes with themselves. It is therefore helpful to understand how this threat to independence and autonomy and fear of dementia extends to younger people, such as the carers of people living with dementia. Gilleard and Higgs (2010), situate the threat these images and stereotypes hold within a wider discourse about social constructions of the third and fourth age. The third age, characterised by choice, autonomy and citizenship is referred to as 'successful ageing' or 'ageing well' and is often accompanied by attempts to defy or reject ageing. In contrast the fourth age can be considered 'real old age' or 'deep old age', a time devoid of agency and choice and characterised by dependency, institutionalisation, incontinence, frailty, and dementia. With increasing value placed on successful ageing, having dementia locates a person within the fourth age and suggests that they have "failed the living well test" (McParland et al 2017:87). Higgs and Gilleard (2015, 2017) refer to the fourth age as a social imaginary, a widely

shared view of how individuals, “imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met and the deeper normative notions and images that underlie all these expectations” (Taylor 2002:106). They suggest that the fear and abjection that the fourth age instils in individuals is as great for those not directly affected by it, as it is for those who are considered to be in the fourth age (Higgs and Gilleard 2015, 2017). This social imaginary of the fourth age, the double stigma of dementia and ageing and the subsequent positioning of people living with dementia and their carers has considerable overlap with the earlier discussions of the causal attributions that carers made when faced with the possibility of dementia, and the personal relevance a label of dementia held for them. But it appears to be the specific threat that these images pose to independence and autonomy that influences the carers response and their help seeking decisions.

To preserve independence, autonomy and the way of life, carers in the qualitative phase of this study responded with increasing practical support for the person living with dementia but avoided talking about dementia. The response of carers to their caregiving situation is considered in the literature in two ways: studies of pre-defined coping strategies (such as problem-focused or emotion-focused coping) which are usually quantitative and linked to outcomes such as depression and anxiety, and qualitative studies exploring the ways in which carers respond to situations throughout their caregiving journey. Although consideration of the carer’s responses pre-diagnosis are limited, they are included in some qualitative studies, and the theories and typologies proposed from these studies are useful in helping to explain how the carer response may prevent help seeking for a diagnosis. Following a brief overview of the dementia carer literature focused on pre-defined coping strategies, four theories and typologies of coping derived from qualitative studies with carers pre and post diagnosis will be used to explore how the carer’s response to a threat to independence and autonomy may have prevented help seeking for a diagnosis in this study.

8.5.1 Coping Strategies

Coping can be described as the cognitive and behavioural responses of an individual to a situation perceived as stressful, for example one that is threatening, harmful or challenging and taxes an individual’s available resources (Stephenson et al 2016). Three types of coping strategies are considered in relation to carer coping – problem-focused coping which aims to solve or change the situation by defining the problem, considering possible solutions and putting these into place (Lazarus and Folkman 1984); emotion-focused coping which aims to

reduce the emotional distress associated with a situation (Lazarus and Folkman 1984); and to a lesser extent relationship focused coping, which takes into consideration the interpersonal nature of the caregiving relationship and importance of maintaining social relationships during stressful situations (DeLongis and O'Brien 1990). Emotion focused coping has been reported more than problem focused coping among carers of people living with dementia (Monteiro et al 2018). Positive emotion focused strategies are more common than negative ones and have included acceptance, emotional support of others, humour, positive reframing, and religion. Negative emotion focused strategies have included behavioural disengagement, denial, self-distraction, self-blame, substance use and venting (Monteiro et al 2018). The problem focused strategies most frequently used by carers of people living with dementia are active coping, instrumental support from others and planning (Monteiro et al 2018).

Carers in the qualitative phase of this study used some negative emotion focused strategies including denial and self-blame in the form of guilt, but they also used problem focused strategies such as gaining instrumental support from family members. Wishful thinking, avoidance and denial in dementia caregiving have been associated with negative outcomes related to mental health and depression, whereas problem focused coping, acceptance and social-emotional support have been associated with positive outcomes (Gilhooly et al 2016). This suggests that carers, such as those in the qualitative phase of this study, who used avoidance and denial could be at risk of poorer mental health.

Several factors can influence the use of coping strategies including an individual's perceived control over the situation, the perceived threat the situation poses, personality factors and the degree of social support (Stephenson et al 2016). Despite having cared for the person living with dementia for a considerable length of time before diagnosis, some carers in the qualitative phase of this study saw the diagnosis as the formal start of their role as a carer. Carers in the systematic review of this study also cited their future role as carer, as a reason to not seek help for a diagnosis. The extent to which a carer views themselves as being in a caring role may determine their coping strategies and the dynamic nature of coping means that carers of people living with dementia will use different coping strategies, influenced by different factors, at different points, along their caregiving career. To understand how carers respond to the different situations they are faced with over time and how these responses influence help seeking, qualitative studies exploring the challenges carers face and their response from pre-diagnosis onwards are now explored.

8.5.2 Carer response to a threat to independence and autonomy

Studies exploring the perspective of carers of people living with dementia throughout their caregiving career are numerous and relate both to specific aspects of caring and to how carers respond and adjust as the person living with dementia's disease progresses. The research of four authors who have sought to theorise or conceptualise the response of carers to a threat to independence and autonomy posed by a diagnosis of dementia are now explored. The pre-diagnosis period is not explored in all, but the theories developed may help to explain the response of carers who do not seek help for a diagnosis.

Based on interviews and case studies with carers of people living with dementia, Clarke (1999) developed a theory of normalisation in which carers "define and continually redefine the person with dementia and their relationship as normal for themselves" (p713). Clarke (1999) states that the theory, "operates in relation to the past, the person and the problem-free and is grounded in the relationship of the person with dementia and family carer" (p718). As such, the carer may consider any advantages from medicalising the problem to be at the expense of the person living with dementia's sense of self and their relationship. Three social processes are involved, normalising, interfacing and interacting and although the theory was originally developed to explain the carers willingness to use home care services it can be considered in relation to help seeking for a diagnosis of dementia.

The process of normalising is influenced by the past life of the person living with dementia and the carer, including the degree of reciprocity in the relationship, the sense of obligation towards caring, preservation or loss of the carer's self-identity and the extent to which the carer has adjusted to the changes in the person living with dementia. To facilitate normalising carers use *pacing* to limit physical and emotional exposure to the person living with dementia to maintain the carers self-identity; *confiding* to help the carer identify problems and consider solutions and; *rationalising* where carers are selective about the information they consider relevant to their definition of normality.

In the context of the integrated results of this study carers used pacing to limit their exposure to changes, by not talking about dementia or their concerns and focusing on physical health problems rather than the cognitive changes they were witnessing. Carers focused on what the person living with dementia had expressed previously about their wishes and the importance they placed on independence and autonomy to rationalise and seek alternative explanations. Confiding could help prevent or facilitate help seeking. When carers in the qualitative phase sought confirmation of their rationalisations and practical support, help seeking could be prevented, but when carers in the systematic review sought explanations for the changes they

were witnessing and confirmation of their concerns, help seeking could be facilitated. In the context of the integrated results of this study, pacing and rationalising were used to support normalisation, whereas confiding had the potential to either support or disrupt the carers normalisation.

Interfacing and interacting in Clarke's (1999) theory involves a negotiation of the nature and extent of professional involvement and how people living with dementia, carers and health professionals work together. These processes are based on the perceived needs of the person living with dementia, the carer, and their perception of the services available. Where health professionals do become involved, their interactions tend to be transitory and in response to a perceived need, with the benefit of providing instrumental support to the carer and person living with dementia but supporting normalisations. Carers also control the release of information to health professionals to maintain their normalisations and reduce the risk of compromising the person living with dementia's self-identity.

The focus on contact with health professionals for practical support and/or attending to physical health problems could be seen in the integrated results of this study and by not talking about their concerns, the carer was controlling the information health professionals received. Clarke (1999) also asserts that health professionals determine the appropriateness of their interactions and this could be interpreted as preventing help seeking in two ways in the integrated results. Health professionals, such as GP's who knew the person the living with dementia well, could support normalisations by adhering to the wishes of the person if they had expressed a desire not to be assessed for dementia. Alternatively, if they recognised changes in the person living with dementia but did not discuss these with them or the carer because of their own therapeutic nihilism they could contribute to preventing help seeking. Health professionals could also be seen prioritising their own concerns by assessing and diagnosing the person living with dementia in hospital without prior discussion with the person living with dementia or the carer.

The purpose of normalisation for carers in Clarke's (1999) study was to maintain the identity of the person living with dementia in the context of their relationship. This served to limit the involvement of health professionals who may foreground the diagnosis of dementia by focusing on prognosis, safety, the need for services and carer needs, over getting to know the person living with dementia and what is important to them. However, there are elements of normalising, such as pacing and rationalising, that served to maintain the identity of the carer as well as the person living with dementia. Self-protective coping strategies have been used by

people with early stage dementia to maintain normality and their sense of self and these strategies were supported by their loved ones (Clare 2002, 2003). A more recent study sought to explain how these strategies to protect both the carer and the person living with dementia have been used by carers pre and post diagnosis (Clemmensen et al 2019).

Clemmensen et al (2019) interviewed family carers of people living with dementia and proposed that two types of relative may exist – the protective relative and the decisive relative. In the pre-diagnosis period, the protective relative, although aware of changes in the person living with dementia does not want to admit what is happening or discuss it with others. In an unconscious process they take responsibility for practical issues, and by avoiding exposure of the changes that are taking place and possible conflict in relationships with others, they ensure "the continuation of the identities of the person with dementia and the family" (Clemmensen et al 2019:498). Alternatively, the decisive relative risks conflict with others by expressing their concerns and seeking confirmation from others and only through a resolution of the conflict between the protective and decisive relative, is help sought. Protective relatives continue to find alternative ways of explaining the behaviour of the person living with dementia to others and have difficulty in expressing their own emotions and stresses, at a cost to their own wellbeing. Decisive relatives may withdraw from the situation to maintain their own wellbeing when a balance with the protective relative cannot be found.

In the integrated results of this study the protective relative could be seen as the one who feared the label of dementia, sought alternative explanations and normalised in order to preserve the independence and autonomy of the person living with dementia and protect their way of life. Not discussing their concerns was an important part of this. Clare and Shakespeare (2004) describe the reluctance of carers to acknowledge and discuss concerns about dementia with the person as psychological resistance, with the aim being to "reassure the person with dementia and demonstrate a continuing commitment to the relationship" (p227). In the systematic review support from others could either prevent or facilitate help seeking and it may be the presence of a decisive relative who speaks out about their concerns and seeks a resolution with any protective relatives that determines whether help seeking occurs. If there are more protective relatives than decisive relatives and a resolution is not found, then the withdrawal of the decisive relative may mean that help seeking continues to be prevented. Clemmensen et al (2019) suggest that a relative living with the person with dementia may be more likely to assume the protective role, with others needing to take on the decisive role, or that relatives will take on the role most natural to them. Where there are few close relatives or only one, and they take on the protective role, then this may also prevent help seeking.

The role of the carer in facilitating help seeking for a diagnosis was considered by Keady and Nolan (2003). They referred to the proactive but often covert strategies used by people living with dementia and their carers in the pre diagnosis period as 'working', and carers and the person living with dementia could be considered *working together*, *working alone*, *working separately* or *working apart*. When *working together*, carers and the person living with dementia shared their fears and concerns and sought help early from health professionals who recognised their concerns and acted accordingly. The person living with dementia could be considered *working alone* if they hid their concerns from the carer, but this could also extend to the period after help seeking if the carer and person living with dementia did not get the response they hoped for. *Working separately* describes a situation where the person living with dementia and carer both have concerns but do not discuss these. This situation can be prolonged as both the person living with dementia and the carer work hard to understand and normalise what is happening without discussing it. If *working separately* puts a strain on the relationship between the person and carer or their relationship was strained to begin with, this may result in *working apart*. Keady and Nolan (2003) propose that it is the quality of the previous relationship between the person living with dementia and carer that determines the extent to which they work together in the pre-diagnosis period, along with a willingness for the person living with dementia to express their concerns and for the carer to hear them. The sharing of awareness and the constructing of a shared narrative between the person living with dementia and their carer both before and after diagnosis can support their coping efforts, decision making and strengthen their relationship, alternatively, denial by the person living with dementia and/or carer may eventually damage the relationship (Clare and Shakespeare 2004, Steeman et al 2006, Cross et al 2018). The integrated results of this study represent carers who are *working separately* or *working apart* from the person living with dementia. There was evidence in the qualitative phase that some people living with dementia were aware of the changes that were happening to them, so they could be considered as *working separately*. Although as the length of time before diagnosis was prolonged, some may have moved to *working apart*. The absence of discussions about concerns prevented a shared narrative being constructed and could work to silence the person living with dementia if they wished to express their concerns.

The quality of the relationship prior to the onset of dementia can influence the wellbeing of the person living with dementia and carer as dementia progresses (Keady and Nolan 2003, Ablitt et al 2009). Four types of caring relationships between people living with dementia and carers have been proposed– Continuity, Reciprocation, Detachment and Duty (Ablitt et al

2009). The type of relationship the carer and person living with dementia have depends on the carer's perception of the changes in the person, the carers motivations to care and the quality of their previous relationship. In the continuity relationship, carers seek to maintain the identity of the person living with dementia, with positive outcomes for the both the person and carer. But this may continue for long periods of time and it is possible that the carer may reach a point of "sudden and delayed realisation" about the severity of their loved one's dementia precipitating a move to a relationship of detachment or duty (Ablitt et al 2009:504). In these two relationships the carer no longer perceives a connection between the person living with dementia's prior self and the person they are now caring for. This sudden point of realisation for carers in a continuity relationship could be the point of diagnosis for carers in the qualitative phase of this study, particularly as some described their relationships as increasingly task focused post diagnosis. However, carers in the qualitative phase of this study also exhibited elements of Ablitt et al's (2009) reciprocation relationship, whereby they make ongoing changes to their relationship with the person to protect themselves from a sudden and delayed realisation of loss.

Similar to the continuity relationship, an early study of family carers found that protecting loved ones from threats to their self-image, by minimising their difficulties and maximising their sense of independence, was more important to carers than providing instrumental care (Bowers, 1987). However, protecting the person living with dementia from what is happening to them can be seen as paternalistic and potentially damaging if sustained for long periods (Nolan et al 1995). Both the continuity and reciprocation relationship types have elements of self-protection that can be seen in Clemmensen's (2019) protective relative and could represent those *working separately* in Keady and Nolan's (2003) study. In the continuity relationship the carer is maintaining the identity of the person living with dementia and at the same time protecting themselves from the changes that are happening. In the reciprocation relationship, they are making changes to the relationship to protect themselves from loss. Striving to maintain identity is acknowledged as an important factor challenging the relationship between the person living with dementia and their carer (Conway et al 2018). Maintaining a sense of self for the person living with dementia results in positive outcomes for the person and their carer, but carers may actively resist the label of carer in order to maintain their own sense of self and identity (Conway et al 2018). As some carers in the qualitative phase and systematic review of this study associated diagnosis with becoming a carer, not seeking help may have helped them to maintain their own sense of self and identity. However open communication and incorporating dementia into a shared story is important and

negative responses to the diagnosis by carers, such as a fear of being able to cope and anticipating loss can impact on the relationship (Conway et al 2018). Carers in the qualitative phase of this study spoke of how their relationship with the person living with dementia became a task focused one, rather than an emotional one and the fact that they were not able to discuss what was happening with the person living with dementia may have influenced this. By continuing to not talk about dementia and protect the person and themselves from what was happening there was the potential for long lasting damage to the relationship between the carer and person living with dementia.

8.5.3 The contribution of theory to the carer response to a threat to independence and autonomy

There is congruent qualitative evidence describing the ways in which carers respond to threats to independence and autonomy throughout their caregiving career, and this lends itself well to helping explain what may be happening in the pre-diagnosis period. The limitation is that carers in these studies all reach the point of diagnosis, and it is not always clear if they actively sought help or how the diagnosis arose. It is possible that other factors influence the point of seeking help in addition those described above. The quality of the relationship between the person living with dementia and carer is often referred to as the important factor that determines whether concerns are shared and how the carers and person living with dementia move forward with these concerns, although what specifically constitutes 'quality' in the relationship is often not clear.

The consideration of the meaning of independence and autonomy and the theories and typologies described here are now used to explain how the carer's response to a threat to independence and autonomy may prevent help seeking for diagnosis of dementia. It begins with a combination of the negative images of dementia and ageing held by carers, as processes that result in a loss of independence, autonomy, self, and identity. As they become aware of changes in their loved one and consider this may be dementia, they become fearful about what the changes might mean for their own sense of self and identity, the person's sense of self and identity and what this might mean for their relationship. They reflect on the value the person living with dementia places on independence and autonomy and choose to support the person in practical ways. Based on their past relationship and their wish to maintain the current status of their relationship, they do not discuss their concerns, or if they do and these are not welcomed by the person living with dementia, they do not try again. They normalise changes and limit the information they share when in contact with health professionals and

others to avoid a conversation about the possibility of dementia. In this way, they feel they are protecting the identity of the person living with dementia and themselves but are not seeking help for a diagnosis.

If this were the full explanation for the mechanism preventing help seeking, then for carers who **do** seek help, it would suggest that they are either not aware of dementia and as such do not have negative images that pose a threat and prevent help seeking or that they have positive images of dementia, where the person and their carers can be supported to retain independence and autonomy and a sense of self as dementia progresses. Although this is possible, as determined earlier, these images do not predominate in the media and carers would have needed to have experienced this previously themselves or know people living with dementia and their carers who have had such positive experiences. Carers would also need to feel that they had the necessary resources to cope with the caring role and based on their prior relationship with the person living with dementia, feel able to share their concerns. So, in addition to providing practical assistance they would support the person in the help seeking and diagnostic process. This suggests that another factor is necessary to counterbalance these negative images that pose such a threat to facilitate help seeking.

8.5.4 Proposition 2

It is now possible to make a proposition as to how the carer's response to a threat to independence and autonomy can prevent help seeking for a diagnosis of dementia (Figure 8.3)

It is proposed that under certain conditions, the possibility of dementia may pose a threat to the social constructs of independence and autonomy, and it is this threat that prevents help seeking for a diagnosis of dementia. The conditions that may influence this threat to independence and autonomy are the internalised negative images and consequences of the biomedical model of dementia, a threat to carer sense of self and identity, a threat to the person living with dementia's sense of self and identity, the value placed on independence and autonomy by the person living with dementia, the quality of the relationship between the person and carer and not sharing concerns. The threat leads to fear in the carer and results in normalisation and practical support but not help seeking for a diagnosis and has the potential for a negative impact on the relationship between carer and the person living with dementia in the longer term.

The mechanism of stigma is considered necessary for preventing help seeking for a diagnosis, and a threat to independence and autonomy has a tendency to prevent help seeking.

However, there is one further context that has arisen in the discussion of stigma, in the carer response to a threat to independence and autonomy and in the integrated results that warrants further exploration – the role of the social network.

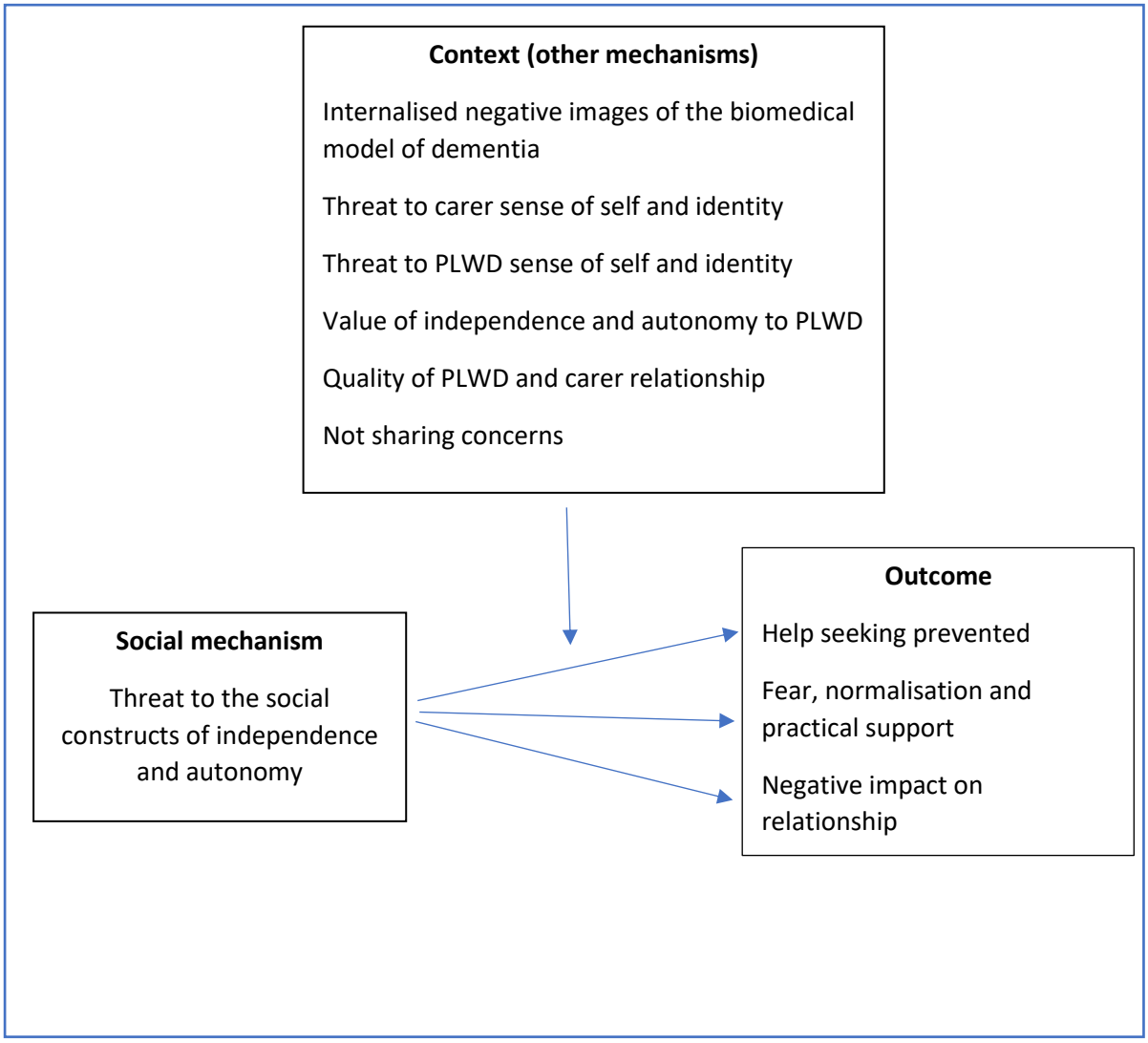

Figure 8.3 Proposition 2 Threat to Independence and Autonomy

8.6 The role of the social network

The integrated results showed that the informal social network has the potential both to prevent and facilitate help seeking for a diagnosis of dementia and that although people living

with dementia and carers may be in contact with health professionals, this does not necessarily lead to assessment and diagnosis. This section will use the framework of the Network Episode Model (NEM) (Pescosolido and Boyer 2010) to explore how social networks for the carer of the person living with dementia may influence help seeking for a diagnosis of dementia. Although there is much research related to the concepts of social networks, social support and social capital, the framework of the NEM incorporates all these elements and specifically how they may interact to influence an individual's illness career.

8.6.1 The Network Episode Model

Pescosolido (2011) defines social networks as "the structural element of the mechanism of social interaction" (p3). They are the building blocks of personal social support systems, therapeutic relationships with health professionals and the health care systems within which these relationships take place. Individuals in social networks are connected by 'ties' and it is these ties that are often the focus of studies of social networks (Pescosolido 2011). For example, social network approaches may focus on the size or content of an individual's network ties or the way in which network ties connect groups of individuals. Research into social capital focuses on the positive potential of network ties such as trust, solidarity, reciprocity, with research into social support focusing on the availability and effectiveness of network ties. Social networks and the ties that connect individuals are complex, they can be positive or negative, helpful or harmful, latent or active, strong or weak and almost certainly dynamic. They therefore have the potential to help explain how the onset of illness is experienced and how or why people respond to it in the way that they do (Pescosolido 2011).

The Network Episode Model (NEM) was developed from the perspective of mental illness and the most recent revision of the model considers not only the interactions of individuals experiencing illness, interactions within and between health and social care organisations, but how the social network context may influence the cause of illness as well as the consequences of it (Figure 8.4) (Pescosolido 2011). The NEM focuses on an entire 'episode' and "sees health and illness behaviours as an embedded social process that creates an illness career" (Perry and Pescosolido 2015:117). This illness career is at the centre of the model, and social networks are the mechanisms that connect the levels and have the power to influence the illness career (Pescosolido 2011). Pescosolido (2011) argues that the inclusion of biological system networks and genetic system networks in the NEM Phase III allows for research aimed at understanding how interactions at these levels influence the development and outcomes of illness careers and how interactions at levels above the illness career may impact on biological and genetic

systems. Although research at these levels will not be considered in this thesis, there is increasing evidence to suggest that poor social engagement and loneliness may have an impact on biological system networks and increase the risk of developing dementia (Penninkilampi et al 2018).

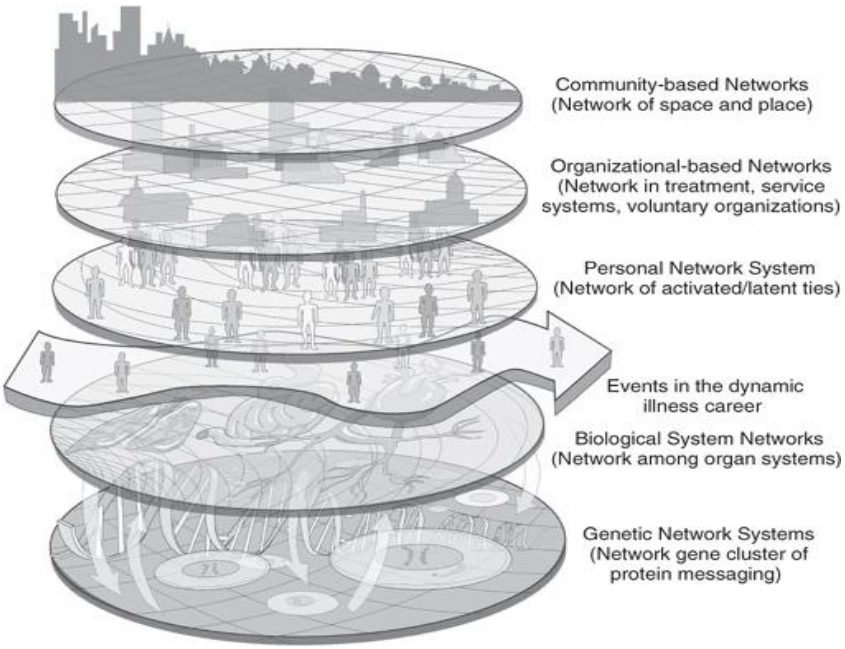

Figure 8.4 Levels of the Network Episode Model Phase III (Pescosolido: ©Sage Angus Clarke 2011)

The NEM proposes that network ties may influence help seeking in numerous ways (Perry and Pescosolido 2015). Network ties can determine the meanings and attributions that individuals hold about certain illnesses, and these attitudes may influence how the person responds to symptoms, determining whether they discuss their health problems and who with. Networks can provide information, support and encouragement to access health services or may attempt to control health behaviour or express stigmatising views (Perry and Pescosolido 2015). The network ties of health professionals form the norms and cultures within organisations that determine the health professional's response to patients and carers, which in turn will influence whether people engage with treatment or care.

The underlying mechanisms explored so far in this chapter have recognised the influence of social processes at the macro level, in the way society influences causal attributions and the self-stigma felt by the label of dementia and the social constructions of independence and autonomy and the extent to which these are congruent with a dementia diagnosis. When

exploring the carer response to a threat to independence and autonomy, social processes at the micro level in the relationship between the carer and the person living with dementia and at the meso level in the extent to which they shared information with others and health professionals were also key. Consequently, there is a role to be played by the interaction of social network ties at different levels in influencing help seeking for a diagnosis of dementia that is worth further exploration.

Research explicitly using the NEM to study social networks and dementia is hard to find, but some studies have explored social networks in the context of dementia at different levels of the framework and those focusing on interactions at the personal network system with some overlap to the organisational based networks level are now considered. In comparison to other models designed to explain help seeking the NEM is considered to better capture the complexities of help seeking and to take into consideration that the pathway into health services is not always one based on rational choice (Berard et al 2020).

8.6.2 Social network interactions of carers of people living with dementia

Qualitative studies are particularly well placed to explore how carers of people living with dementia interact with their social network. In the qualitative phase of this study carers relied on their social network ties to support them practically in caring for the person living with dementia. In a study by Donnellan et al (2015, 2017), spousal carers of people living with dementia sometimes actively resisted support from adult children and in-laws to maintain their own independence and justified this by not wanting to overburden others who had competing demands. Increasing family contact may represent the increasing needs and impairment of the person living with dementia and may be seen as a threat to the independence and autonomy of the carer (Donnellan et al 2017). Carers in other studies have valued being able to control who they accept support from, preferring emotional support from people in similar circumstances as them, although again, some find accepting help from others difficult if they are not used to depending on other people (Cross et al 2018). It is possible that carers may not seek support from their network ties in the pre-diagnosis period if they feel that the help offered or the need for help is a threat to their own independence and autonomy and as such any positive encouragement to seek help for a diagnosis from network ties could be missed or even ignored. Perry and Pescosolido (2010) refer to the functional specificity hypothesis in which “individuals engage in selective and purposive activation of ties” (p346), selecting individuals in their network who are likely to be the most useful, sympathetic or knowledgeable in a particular situation, such as a health crisis. It is possible that when carers in

the qualitative phase of this study sought practical help from their social network ties, they selected those people who were the least likely to threaten their independence and autonomy by supporting them practically, but not encouraging them to seek help for a diagnosis. This network selectivity could also be seen in a study by Daly et al (2012) in relation to contacts with health care professionals as well as the informal social network.

Daly et al (2012) proposed a theory of 'Sustaining place' where 'place' is linked to the social identity of the carer and the extent to which they feel situated in personal, social, and organisational relationships related to their caring role. Carers move from an 'unsettled place' pre-diagnosis as they seek explanations for changes, to a 'threatened place', where they are aware of stigma and the meanings attributed to dementia by others. Carers become sensitive to their interactions with others and negative and unhelpful interactions with health professionals can leave them feeling abandoned. They use "protective, defensive and inter-relational strategies" (Daly et al 2012:505) to sustain place and prioritise and protect the person living with dementia and seek space and support to nurture themselves. This supports the findings in the qualitative phase of this study where carers created a bubble of normalisation to protect and preserve the way of life for the person living with dementia and themselves. As part of this carers missed opportunities to discuss their concerns with health care professionals, choosing instead to use the services that focused on physical health or practical care rather than those that may lead to a diagnosis of dementia. Daly et al (2012) suggest that carers surround themselves only with others who are 'supportive of place', and in their contacts with health and social care they look for specific services and do not pursue routes that are unsupportive of place or too time intensive. This has similarities to Clarke's (1999) theory of normalisation discussed earlier, where carers were selective of the information they shared with health care professionals in order maintain the identity of the person living with dementia and themselves.

Cohesive support networks have the potential to create a sense of purpose and shared narratives for people living with dementia at the end of life and this cognitive social capital (shared meanings and interpretations) has an important influence on the decision making of carers and health professionals (Sawyer et al 2019). This can be positive if based on knowledge of the person living with dementia but negative and discriminatory if based on paternalistic agendas (Sawyer et al 2019). Sawyer et al (2019) saw social networks diminishing as dementia progressed and proposed that this could result in paternalistic care and be a catalyst for entry into the fourth age. The fear of which, this thesis proposes, may prevent help seeking for a diagnosis of dementia. It is possible that if carers in the qualitative phase saw paternalistic

attitudes in their encounters with health professionals pre-diagnosis, this combined with their fear of the fourth age prevented them expressing their concerns about the possibility of dementia. The formation of cohesive social networks at an early stage is likely to have lasting benefits, empowering the person living with dementia throughout their life, preserving their identity (Sawyer et al 2019). There is potential then for social networks to 'sustain the place' of the person and carer throughout the disease process, and anticipation of this may reduce any threat to independence and autonomy that a diagnosis could bring, encouraging help seeking. Carers in the qualitative phase of this study talked very little about their social networks and it is possible that they did not have social networks which they felt would 'sustain their place'. In the systematic review of this study informal social networks could be a barrier to help seeking when network ties were not supportive of the carer's concerns and carers rarely sought help without informal network support. Further confirmation of the importance of social network ties in the help seeking process.

Perry and Pescosolido (2015) proposed that the mechanism that connects network tie activation and network influence is health discussion. The absence of discussions about the carers concerns and the subsequent diagnosis was a striking finding of the qualitative phase of this study and carers in some studies in the systematic review had difficulty discussing concerns with the person they cared for. Perry and Pescosolido (2010, 2015) found that people with mental illness were more likely to discuss their health problems with people who had similar experiences and that older people and people with more severe symptoms were more likely to connect with others to discuss their health. This may support the finding in the systematic review that recognition of a problem by carers as symptoms became more severe facilitated help seeking. But carers in the qualitative phase did not seek help as the person they cared for became more severely impaired. Some carers in the qualitative phase had family or friends in a similar situation to them, but they used these experiences to make downward social comparisons to their own situation, supporting their normalisations and alternative explanations, rather than using these social network ties to discuss their concerns. So, knowing others in a similar situation is not enough on its own to encourage carers to share their concerns. Participants in Perry and Pescosolido's studies (2010,2015) were more likely to discuss health concerns with partners and mothers and people were no more likely to discuss their concerns with health professionals than within their informal network. This finding is supported in the qualitative phase of this study as carers not only did not share their concerns with the person they cared for, they did not share concerns with health care professionals either. Discussions of health took place within strong relationships where there was frequent

verbal or face to face contact and low levels of conflict (Perry and Pescosolido 2010,2015). Health discussions were also more likely to take place in smaller networks with greater trust in health professionals. As discussed previously the quality of the relationship between the person living with dementia and carer determines how the carer responds to the changes they witness in the person living with dementia but it is likely to also influence whether they share their concerns. The characteristics associated with initiating health discussions in Perry and Pescosolido's (2015) study – being older, having more severe symptoms and having a partner/ mother to share concerns with – may have implications for adults caring for parents, particularly mothers, with early symptoms of dementia, as was the case for many carers in the qualitative phase of this study. This may mean they are less likely to discuss their concerns or feel they have someone to share them with. The moral dilemma of seeking help on another's behalf is often expressed by carers (Perry-Young et al 2018) and the ability to share and discuss concerns with the person living with dementia and others would seem to be a way to resolve this dilemma. However, carers and people living with dementia have been found to conceal their diagnosis if they believe they will be stigmatised by others in their social network (Brossard and Carpentier 2016). The extent to which a social network supports carers post diagnosis may also depend on the meanings attributed to dementia by social network ties (Tatangelo et al 2017). So, carers such as those in the qualitative phase of this study, may choose not share their concerns if they are aware of stigmatising views within their social networks, in order to preserve the social network support that they currently have.

8.6.3 The contribution of theory to the role of the social network

The scope of research on the social networks of carers of people living with dementia is wide, but evidence for specific aspects of the role of network ties in help seeking is quite limited. The NEM and research in mental illness suggests that network ties are important when deciding who to discuss concerns with and this may have relevance for carers of people living with dementia sharing their concerns and deciding whether to seek help for a diagnosis. Research on health discussions is related to mental illness so one cannot assume that the factors influencing health discussion in the research discussed here are the same for carers of people living with dementia. But it is clear that the discussion of concerns is an important factor in the help seeking process. The specific characteristics of network ties that support or prevent the sharing of concerns for carers of people living with dementia are worthy of further exploration.

The types of carers in the studies discussed here are diverse, some include spousal carers only, and other studies include all informal carers of people living with dementia. Therefore, it is

possible that the influence of the social network may differ depending on the familial relationship of the person and their carer. There is evidence to suggest that carers are selective in who they access for support and the factors influencing their selectivity such as preserving their identity, their independence and autonomy may be important when carers select who to seek support from and share their concerns with, both formally and informally in the pre-diagnosis period.

The NEM is helpful in explaining the potential in the integrated results of the informal social network preventing or facilitating help seeking. As carers become aware of the possibility that their loved one has dementia they are influenced by negative images of dementia and ageing as processes that result in a loss of independence, autonomy, self, and identity. These beliefs will have been determined to some extent by their network ties and their exposure to others in their network caring for people living with dementia. These contribute to a fear of the label of dementia that results in normalisations, seeking alternative explanations and the desire to preserve independence, autonomy, and their way of life. The meanings attributed to dementia by the social network, such as cultural interpretations of dementia as part of normal ageing or stigmatising beliefs, will determine whether the carer shares their concerns with network ties or not. The characteristics of network ties such as strength, frequency of contact and beliefs about health professionals may influence whether carers share their concerns. If they discuss their concerns with network ties and are met with stigmatising attitudes or their concerns are dismissed, they may not discuss these again. If carers encounter paternalistic attitudes in their encounters with health professionals, this may also prevent them from expressing concerns. As the challenges faced by the person living with dementia and carer increase, the carer will be selective in seeking practical support from those who can help to maintain the carer's independence and autonomy and the sense of identity for the carer and person living with dementia. But this will not include seeking help for a diagnosis. Information given to and support from health professionals will also be selected to ensure independence, autonomy and identity is maintained, rather than seeking a diagnosis.

In sections 8.4.4 and 8.5.3, stigma and the carer response to a threat to independence and autonomy played key roles in preventing help seeking for a diagnosis of dementia. But they were not considered to provide a full explanation. If the role of social network ties is to complete the picture, then in addition to how they prevent help seeking, they should also play a role in facilitating help seeking. The following describes how this could happen.

The carers' social network ties may be aware of positive images of dementia, where people living with dementia and their carers can be supported to retain independence and autonomy and a sense of self as dementia progresses, in addition to the negative images that feature predominately in the media. This may come from their own experience or experience within their own network ties. If the carer has network ties with characteristics that support health discussions, when they do share their concerns, they will be met with understanding, information, and assurance that their network ties will support them to maintain independence, autonomy, and identity in the event of diagnosis. Their network ties could support the carer emotionally and practically in talking to the person living with dementia and in seeking help. Interactions with health professionals for physical problems could be positive and supportive of independence, autonomy, and identity and as such carers could feel confident that discussing concerns with health professionals may not pose a threat to their way of life.

It therefore appears that social network ties are an essential mediating factor that can either prevent or facilitate help seeking. In the presence of stigma associated with a poor prognosis and a threat to the independence, autonomy, and identity of the person living with dementia and carer, the social network ties of the carer, both formal and informal, can reinforce these beliefs and prevent health discussions. Or they can provide a balanced view, encourage sharing of concerns and reassurance that the support they can provide will preserve their independence, autonomy, and identity.

8.6.4 Proposition 3

It is now possible to make a proposition as to how the social network has the potential to prevent help seeking for a diagnosis of dementia (Figure 8.5).

It is proposed that under certain conditions the social network may prevent help seeking for a diagnosis of dementia. The conditions under which the social network has the tendency to prevent help seeking are network ties that share negative understandings of dementia and support its threat to independence and autonomy, stigmatising responses or dismissal of concerns from network ties, characteristics of network ties that do not support sharing of concerns and the paternalistic attitudes of health professionals.

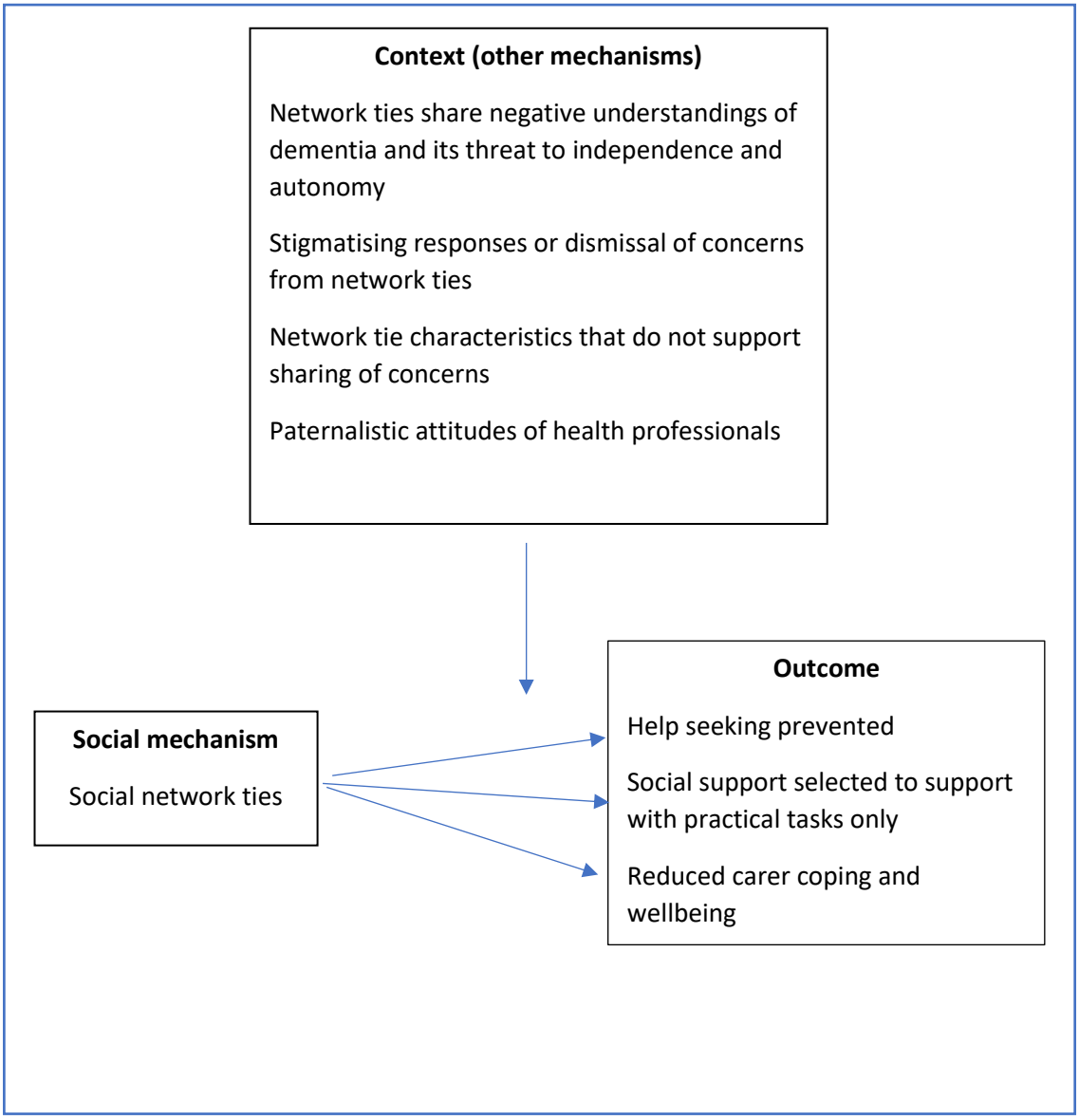

Figure 8.5 Proposition 3 The influence of social network ties

8.7 A model of the prevention of help seeking for a dementia diagnosis

In this chapter the integrated findings presented in Chapter Seven have been recontextualised and interpreted using existing theory and research through a process of abduction. This consideration of the findings was then subjected to a process of retroduction, whereby abstract and counterfactual thinking were used to propose what needs to exist for help seeking for a dementia diagnosis to be prevented. The findings of critical realist research take the form of theoretical generalisations aimed at "providing knowledge of structures, their mechanisms and tendencies" which can then be applied to specific contexts (Danermark et al 2019:203). This chapter has identified the mechanisms of three social structures that may prevent help seeking for a diagnosis of dementia and the contexts within which these

mechanisms have the tendency to prevent help seeking, along with possible outcomes. These will now be combined to produce a model of the prevention of help seeking for a dementia diagnosis that could be used in future research to determine if the mechanisms proposed and the outcomes produced hold true (Figure 8.6).

The two mechanisms of stigma and a threat to the social constructs of independence and autonomy are closely interlinked. They both require the carer to have some knowledge or awareness of dementia in order to be influenced by the negative images often presented by a biomedical model of dementia portrayed in the media. The threat these images pose to a sense of self and identity for the carer and person living with dementia reinforces negative causal attributions and stereotypes about dementia and ageing, that carers are aware of from childhood, experience, or social network ties. Although the role of health professionals was explored only from the carer's perspectives in the qualitative phase of this study, existing research has helped to propose how the perception of the involvement of health care professionals in the pre-diagnosis period could prevent help seeking. It is possible that health care professional's own beliefs and therapeutic nihilism prevent them from discussing their own concerns or enquiring about concerns. Health care professionals may be following the wishes of the person living with dementia who does not wish to be assessed. Alternatively, the carer's experience of health care professional involvement may deter them from discussing their own concerns as they fear their own and the person living with dementia's independence, autonomy and identity may be compromised if they do.

The carer's main concern is protecting the person living with dementia and their knowledge of the value placed on independence and autonomy by the person, leading to normalising behaviour and practical support. As the studies discussed here and previous reviews have shown, strategies aimed at maintaining the person living with dementia's identity, independence and autonomy are common as the person and carer adjust to the diagnosis of dementia (Bunn et al 2012). But when these strategies are employed in the pre-diagnosis period, they have the potential to prevent help seeking for a diagnosis without an intervening influence. This intervening influence are the social network ties of the carer. The influence of these network ties is essential in both preventing and facilitating help seeking. When network ties share and reinforce the negative images of dementia as a threat to independence, autonomy and identity, carers hold back from discussing their concerns with the person living with dementia. They do this from a place of concern, to preserve the way of life for the person and maintain their identity. But in doing so they prevent the voice of the person living with dementia being heard, denying them opportunities to discuss how they feel and what they

would like to happen. Characteristics of the carer's social network ties may prevent any further sharing of concerns or discussion about help and if these do take place and the carer's concerns are dismissed, then further action may be prevented. The carer and the person living with dementia continue *working separately* as in Keady and Nolan's study (2003), with the carer and their social network providing increasing amounts of practical support to the person living with dementia. However, the emotional needs of the person and carer are unlikely to be met as they continue to not discuss what might be happening. This has the potential to damage the future relationship between the person living with dementia and carer, as the person living with dementia can be undermined or silenced and reduce the carer's capacity to cope if they do not seek emotional support from their informal network. The extent to which these outcomes were present in this study was not explored but could be by including information about diagnosis help seeking pathways in future studies which aim to measure relationship, coping and wellbeing outcomes.

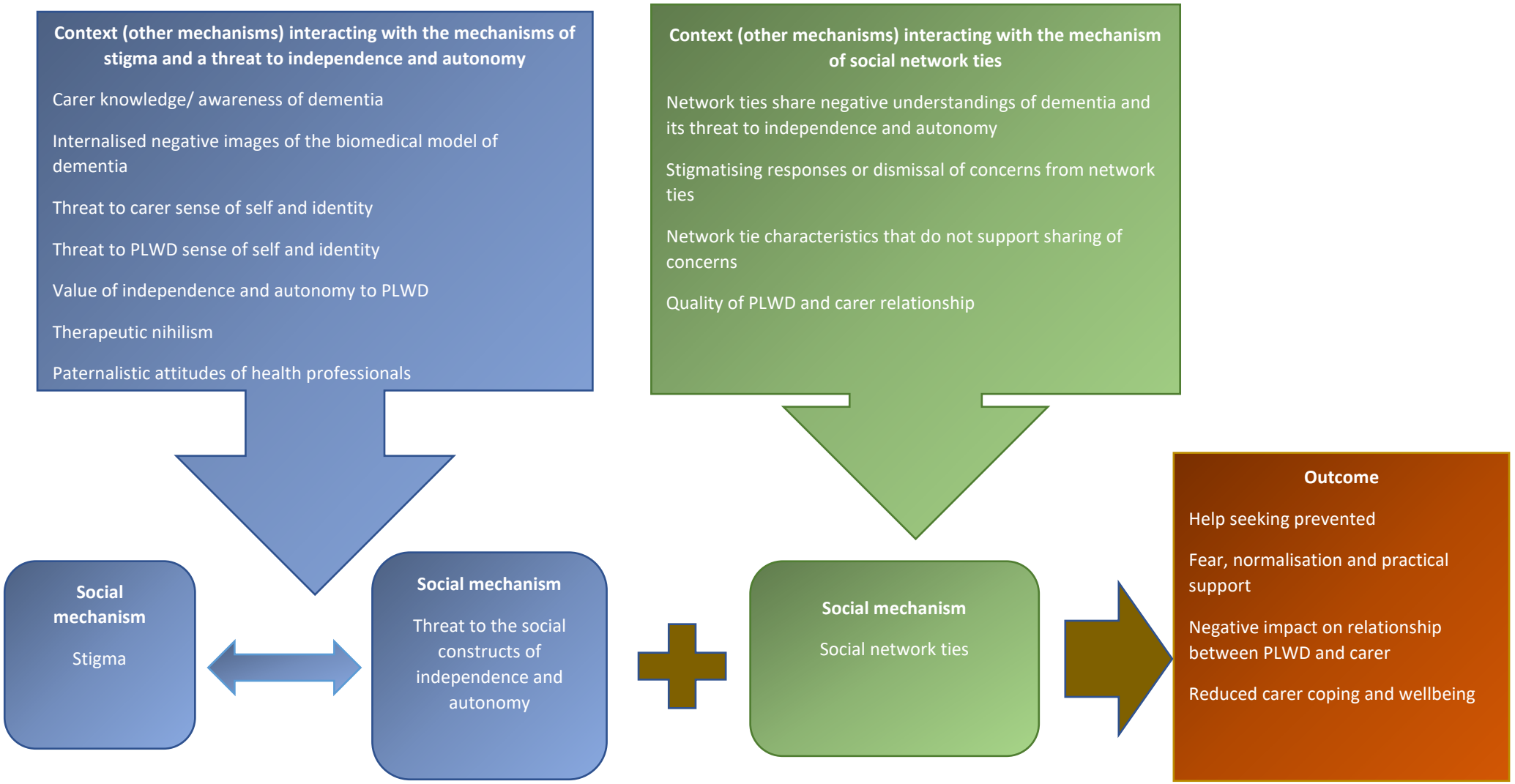

Fig 8.6 Model of the prevention of help seeking for a diagnosis of dementia

8.8 Summary

In this chapter the evidence for three social mechanisms has been discussed. A model to demonstrate how the mechanisms have the potential to interact to prevent help seeking for a diagnosis of dementia has been developed. The next chapter will consider how future research could be employed to provide support for this model and how the social issues underlying these mechanisms could be addressed to facilitate help seeking in the future.

Chapter 9 Conclusions and Recommendations

To the researcher's knowledge this is the first study conducted to explore why people may not seek help for a diagnosis of dementia through the study of a group of people who were not actively seeking help for a diagnosis. This concluding chapter starts with a brief overview of the methods used in the study and the results, followed by the strengths and limitations. The contribution of the study findings to the existing body of evidence are outlined along with the implications of the findings for practice and research. Recommendations are made related to changes at a practice and policy level that would encourage timely diagnosis.

9.1 Overview of methods and results

This study used a convergent mixed method design within a critical realist framework to understand why people may not seek help for a diagnosis of dementia through four study phases. The first, a systematic review of the barriers and facilitators to help seeking for a diagnosis of dementia from the perspective of carers and people living with dementia, identified ten barrier themes and three facilitator themes. Carers and people living with dementia experienced multiple barriers which often required more than one facilitator to seek help. Denial, stigma and fear and a desire to preserve the autonomy of the person living with dementia contributed to the normalisation of symptoms, with the informal network playing a key role in the help seeking process.

The qualitative phase involved interviews with 12 carers of people diagnosed with dementia following an acute hospital admission. A thematic analysis of the data illustrated how carers created a 'bubble of normalisation' around themselves and the person living with dementia, to construct explanations that rejected a label of dementia and protected the person from a loss of independence, discrimination and prejudice. Carers struggled to talk to the person about dementia and there were missed opportunities to initiate the help seeking process as they encountered health care professionals. The diagnosis burst their bubble and left many feeling unsupported, still unable to talk about dementia and questioning the value of the diagnosis.

The quantitative phase of the study involved an analysis of 1830 referrals to a memory clinic to examine the characteristics of people referred to a memory clinic by their GP or via the acute hospital and to determine factors associated with receiving a diagnosis of dementia and survival following a diagnosis. People referred to the memory clinic by the acute hospital were significantly more likely to be older and of white ethnicity than people referred by their GP.

People diagnosed with dementia following referral from the acute hospital were more likely to have severe dementia, more likely to have died 12 months post referral and more likely to have had hospital admissions before and after referral. People referred by their GP were more likely to be diagnosed with cognitive impairment or be cognitively intact following their assessment. In the interpretation of these results it was suggested that the older, white population in the sample were more likely to be socially excluded and have reduced social networks which may have influenced their help seeking.

In phase four data from the first three study phases were integrated through a process of listing and matching to determine findings which confirmed, enhanced, or diverged from each other (Johnson et al 2019). This created a narrative of the integrated results and five new integrated themes of 1) fear of the label of dementia, 2) alternative explanations, 3) preserving autonomy, independence and the way of life, 4) the potential of informal networks and 5) the role of health care professionals.

In keeping with critical realist explanatory research, a process of abduction followed whereby the findings which resulted in five integrated themes were described, interpreted and explained in the context of attribution and modified labelling theory related to stigma, coping strategies and the carer response to a threat to independence and autonomy and the Network Episode model. In the process of retroduction, using counterfactual thinking, the proposition of necessary and contextual mechanisms that prevent help seeking for a diagnosis of dementia were made and a model of how these mechanisms interact to prevent help seeking for a diagnosis of dementia was proposed. The model proposed that stigma related to dementia and the threat this posed to independence and autonomy could prevent help seeking when the carer's social network ties shared these views, and the carer was unable to share their concerns with others.

9.2 Strengths and limitations

The mixed method design is a strength of this study. The role of the social network was an important finding of the systematic review and in the interpretation of the quantitative phase results, however it was not explicit in the findings of the qualitative phase. The integration of results from the first three phases ensured that this important factor was considered in the abductive and retroductive analysis and as such, was determined to be an important mechanism influencing help seeking. Therefore, the mixed method design and integration of findings should be recognised as a strength. The quantitative phase of the study was able to

contribute to the integrated findings but overall, the data available for analysis was limited. Recruitment difficulties in the qualitative phase also meant that the carers interviewed were not from the same London borough as the quantitative sample, which had they been, may have contributed to the strength of the integrated results. The use of critical realism as a lesser known paradigm could be considered both a strength and limitation of the study. As critical realism is considered a meta-theory and does not recommend specific methods there are multiple ways of exploring phenomena from a critical realist perspective. This means that although both help seeking and dementia care has been studied separately using a critical realist perspective, comparative data is limited. However as a paradigm it is particularly well suited to a research problem that involves understanding the underlying mechanisms of a phenomenon, such as not seeking help for a diagnosis of dementia, to determine what needs to change to facilitate help seeking for a diagnosis (Blaikie and Priest 2017). As little was known about the experiences of a group of people who were not actively seeking help for a diagnosis, the methodological freedom of critical realism was a strength. There are critics of Bhaskar's version of critical realism, and these tend to relate to what appear to be inconsistencies in some of his philosophical claims (Blaikie and Priest 2017). However, by clearly stating the elements of critical realist philosophy that have underpinned this study, and how critical realism has influenced the study design, the researcher does not feel that these criticisms detract from the overall findings of the study and propositions of underlying causal mechanisms that have been made.

The absence of the voice and experiences of people living with dementia in this study is a limitation. However, the role played by carers in initiating help seeking for diagnosis is a crucial one and the findings are no less valid for representing the carer experience only. The important finding that stigma results in a lack of discussion about concerns for dementia, which in itself can silence the voice of the person living with dementia, means the recommendations of this study seek to prioritize the position and voice of people living with dementia in society.

9.3 Contribution to the body of evidence

Chapter Two described the diverse literature related to help seeking for a dementia diagnosis. This study has added to this literature with a comprehensive systematic review of the barriers and facilitators to help seeking from the perspective of carers and people living with dementia. The qualitative phase of this study adds to the literature on pathways to diagnosis with an analysis of the pathway for a group of carers who had not reached a point of seeking help

when a diagnosis was made, unlike the carers usually represented in these studies. Although there were similarities to previous studies in the way carers noticed and appraised changes in the person living with dementia, stigma played a role not usually acknowledged in pathway studies in preventing help seeking. As the group of carers in this study differ from previous studies it suggests that stigma may be a greater issue than previously thought for people living with dementia and carers who are yet to seek help, and may explain why, despite increases in diagnosis rates, around a third of people in the UK remain undiagnosed (NHS Digital 2019). The quantitative phase of this study adds to the growing body of evidence aimed at understanding memory clinic populations in the UK. The findings highlighted important differences between people who had sought help and been referred by their GP, and people who had not sought help and were identified following an acute hospital admission. Understanding the characteristics of people referred to memory clinics will help commissioners to ensure their services meet the needs of specific groups within a population.

The overview of research using health behavior models to study help seeking for a diagnosis of dementia in Chapter Two acknowledged the need to find models that accommodated the complexity of the help seeking process. As part of the discussion in Chapter Eight, the Network Episode Model (Pescosolido 2010) was used to support the important role of the social network in the help seeking process, an element included in some models but not all. The Network Episode Model has not been applied to the study of help seeking for a dementia diagnosis and could be a better fit model than those used to date. However, this model does not incorporate the element of stigma, that this study now demonstrates is a crucial factor in preventing help seeking. Consequently, a more comprehensive model such as The Framework for Integrating Normative Influence on Stigma (FINIS) (Pescosolido et al 2008) could be a more appropriate starting point for future research. Although developed to provide a theoretical basis for the study of stigma in mental illness, the authors propose it could be adapted and used to study any stigmatising condition. In addition to incorporating behavioural constructs used in other models it also addresses the origins of beliefs that may influence help seeking, as well as the wider social context. Such a framework could be used to synthesise the existing research related to help seeking and dementia diagnosis to determine a focus for future research.

Although previous reviews have reported that dementia related stigma can prevent help seeking or delay diagnosis, they rarely describe how this process takes place (Hermann et al 2018, Nguyen and Li 2020). In 2009 the National Dementia Strategy in England (Department of Health 2009) identified that stigma prevented discussion about dementia resulting in inactivity

or delayed help seeking and set objectives to address public and professional awareness and understanding of dementia. Over ten years later, this study has demonstrated that stigma still prevents discussion about dementia. Stigma that results in delayed diagnosis is most often related to health care professionals (Hermann et al 2018, Werner 2014) and the findings of this study suggest that stigma prevents discussion between health care professionals, carers and people living with dementia throughout the pathway, delaying assessment and resulting in a diagnosis that is not always disclosed to the person living with dementia. The role of stigma in delaying carer help seeking for a diagnosis has been attributed to worry about the person living with dementia's reaction, personal avoidance and a perceived lack of support for the family (Devlin et al 2007). The findings of the present study support this limited evidence base, as carers in the qualitative phase and systematic review worried about the reaction of the person and consequently did not discuss their concerns. In this study stigma related to the threat to independence and autonomy was the main factor preventing help seeking for a diagnosis and as such demonstrates the need for further research that aims to understand how stigma delays dementia diagnosis, so that interventions to reduce stigma are appropriately focused.

The role of the social network as both a barrier and facilitator to help seeking for a diagnosis of dementia was identified in many studies in the systematic review. The qualitative phase, integrated results and subsequent analysis in this study has proposed that the influence of the social network is linked to stigma and perceptions of dementia in society and that this determines whether carers feel able to share their concerns with others. This research adds to the literature on help seeking for a diagnosis of dementia by identifying a need to address attitudes towards dementia more widely if help seeking for a timely diagnosis is to be encouraged.

9.4 Implications for practice

The findings of this study show that there is still considerable work to do in addressing the four cornerstones of a timely diagnosis – timely and accessible diagnosis for all; decreased fear and stigma of dementia; rights and wishes of the person being paramount and diagnosis as a key intervention in the adjustment process to living with dementia (Brooker et al 2014).

The ALCOVE recommendations discussed in Chapter One suggested that a timely diagnosis requires a staged approach which supports adjustment to diagnosis with pre- assessment counselling and a sensitive disclosure, with consideration of where this takes place and who is

involved (Brooker et al 2014). The quantitative phase of this study supports the case finding approach in acute hospitals as an ideal opportunity to identify people who do not seek help in primary care. However, the experience of carers in the qualitative phase of this study suggest that a diagnosis disclosed during a hospital admission may not always be ideal, with the rights and wishes of the person being diagnosed not always discussed and considered. The case finding approach is now part of the standard contract for acute NHS hospital trusts in England. However, this should not preclude further research from determining how this is best delivered and, allowing for local variation, whether guidance to create greater consistency is needed to ensure that a diagnosis initiated in this way truly meets the individual needs of the person being diagnosed and their carers. NICE (2018) recommend referral to specialist memory clinics for diagnosis in the majority of cases, however, there is evidence for innovative primary care involvement in diagnosis that may be more in keeping with an individualised approach to timely diagnosis and reduce the stigma often associated with dementia diagnostic services delivered within mental health settings (Wells and Smith 2017).

If the right time for a diagnosis in the adjustment process to living with dementia is "specific to the unique circumstances of the individual at a particular point in time", then carers and people living with dementia are more likely to seek help for a diagnosis when they perceive there will be a benefit in doing so (Watson et al 2018:8). In the absence of a cure or disease modifying therapy, the proposed benefits of diagnosis, as described in Chapter One, are also likely to be individual, with some people diagnosed with dementia and carers gaining more benefit from a diagnosis than others. If proposed benefits such as psychosocial interventions and support are not widely visible to the public, in the way that medical or pharmacological treatments are, then people in the pre-diagnosis period are not likely to be aware of the potential benefit a diagnosis may bring. Carers in the qualitative phase of this study found relief in the confirmation of their suspicions, but the extent to which they benefited from post diagnostic support and interventions varied, and they often found themselves alone in the search for support and information. They also struggled to maintain the independence and autonomy of the person they cared for post diagnosis, which had been their main aim in the pre-diagnosis period. For people living with dementia and carers to be encouraged to seek help for a diagnosis of dementia there needs to be greater visibility of interventions that support people living with dementia and carers to maintain independence and autonomy post diagnosis. It is acknowledged that post- diagnostic support in England is variable and that integrated, evidence-based services to meet the individual needs of people living with dementia and carers are needed (Department of Health and Social Care, 2016). Consequently,

there could be an argument for increased allocation of funding and resources for post diagnostic support, rather than interventions to increase diagnosis rates, as the visibility of effective post diagnosis support may encourage help seeking for a diagnosis.

There has also been a call for greater focus in public awareness campaigns of the advantages of seeking help for a diagnosis of dementia (Brooker et al 2014). However, the focus of public awareness campaigns in England is currently moving from one of awareness of the signs and symptoms of dementia, to one of the risk factors for and possible prevention of dementia (Department of Health and Social Care, 2019). There has been increased media coverage of the prevention of dementia and despite this being an important public health issue, the way in which this discourse frames dementia can often lay blame with the person living with dementia, holding them responsible for their illness (Peel 2014, Lawless and Augoustinos 2017). As being considered responsible for your own illness is an important stereotype that results in stigma (Corrigan and Kosyluk 2014, Else-Quest and Jackson 2014), the way in which the possible prevention of dementia is portrayed in the media has the potential to reinforce stigma and prevent people talking about dementia and seeking help at a time right for them.

9.5 Implications for research

In using a critical realist perspective to study why people may not seek help for a diagnosis of dementia, the researcher has been able to make a theoretical generalisation of how help seeking might be prevented in the form of a model depicting the structures, contextual mechanisms and outcomes (Figure 8.6). In Chapter Eight the theory used to reach this generalisation has been clearly set out and critiqued. The next step in critical realist research is to test the theoretical generalisation. Future research, studies with other carers of people who have not actively sought a diagnosis of dementia would be the ideal starting point, but using the model in research with carers who actively sought help could identify if the counterfactual conditions considered in Chapter Eight are true. As carers were the focus of this study, the model may not hold true for the experiences of people living with dementia who do not seek help. Therefore, research involving people living with dementia to determine if these mechanisms also apply to their experiences is needed. The stance taken in this critical realist study design was a detached one, but this does not mean that the emancipatory aspirations of critical realist research cannot be realised. The contribution of the study findings to the existing body of evidence, as discussed above, have the potential to increase understanding about how a timely diagnosis could be achieved and how people living with dementia and their carers can benefit from a diagnosis. The researcher acknowledges her responsibility in

ensuring that these findings are disseminated appropriately for this to be possible. The absence of discussion about concerns and the subsequent diagnosis of dementia between social network ties was an important finding of this study. Further research is required to understand the characteristics of social network ties that encourage the sharing of concerns, and factors related to social networks that facilitate health discussions related to dementia. The focus of this research should not only be with carers and people living with dementia but also the public, as the sharing of concerns with network ties is an important factor in help seeking for a diagnosis of dementia.

9.6 Recommendations for policy and practice

In addition to the recommendations for future research already made in this chapter, there are three further areas of focus that have the potential to facilitate help seeking for a diagnosis of dementia. These are dementia friendly communities, a social citizenship approach to dementia and the development of tools to support a discussion about dementia.

9.6.1 Dementia friendly communities

A dementia friendly community is defined as “a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential” (Alzheimer's Disease International, 2016:10). They are seen as a key step to the social inclusion of people living with dementia and acceptance of dementia as a disability in society (WHO and ADI 2012). As a threat to the independence and autonomy of the person living with dementia and their carer was a social structure preventing help seeking for a diagnosis in this study, dementia friendly communities have the potential to reduce this threat and encourage help seeking. Since 2012 in England, government policy to address diagnosis rates has been accompanied by a drive to create dementia friendly communities (Department of Health, 2012, 2015). However, the two are not necessarily linked within policy documents, as dementia friendly communities are seen as a way of improving post diagnosis support, but there is potential for dementia friendly communities to also facilitate help seeking for a diagnosis of dementia. This study has demonstrated the key role that social networks play in preventing and facilitating help seeking for a dementia diagnosis. Greater public understanding of dementia and the positive roles that people living with dementia can continue to play in society after a diagnosis, have the

potential to reduce the stigma that prevents discussion within social networks about dementia and seeking help.

The creation of Dementia friendly communities in England have revolved around two initiatives; the Dementia Friends campaign, aimed at improving understanding of dementia and the ways in which individuals can help people living with dementia in their community; and a recognition scheme for communities who set up Dementia Action Alliances to address issues related to the needs of people living with dementia in their community, making services within their community more accessible (Alzheimer's Society 2020a). Although the targets set by the government for these two initiatives have been met, a more systematic approach to evaluating dementia friendly communities is needed (Department of Health 2019, Buckner et al 2019). Future evaluation, research and policy could focus on the extent to which these initiatives reduce stigma and the potential that greater visibility of people living with dementia being supported and understood can have on the willingness of people to talk about dementia and seek help for a diagnosis. The linking of data on diagnosis rates across geographical areas with the progress of dementia friendly communities within these areas would be one way determine this.

9.6.2 A social citizenship approach to dementia

Stigma, and particularly self-stigma, was a necessary mechanism preventing help seeking for a diagnosis of dementia in this study. A sense of belonging and identity within a community are key features of citizenship that dementia friendly community initiatives aim to achieve (Brannelly 2016). The extent to which this has been successful in dementia friendly communities within England is not always clear (Buckner et al 2019). There is concern that a focus on the creation of dementia specific services and a society that cares for and supports people living with dementia, fails to see people living with dementia as equal citizens and contributors to society (Buckner et al 2019, Lin and Lewis 2015). As such these initiatives may not have the impact they would have hoped to, in addressing public attitudes towards dementia. A greater focus on the rights of people living with dementia to be equal citizens in society may be needed (Buckner et al 2019, Lin and Lewis, 2015). The use of a social citizenship approach to dementia has evolved over the last decade and can be defined as,

> "A relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social

> positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level". (Bartlett and O'Connor 2010:37)

The use of such an approach offers a broader perspective to the dementia discourse including the roles of state and non-state organisations in the lives of people living with dementia, and how the intersectionality of ageism and dementia related stigma contribute to the reduced rights and status of the person living with dementia (Bartlett and O'Connor et al 2010, Bartlett 2016). It is considered that awareness and 'friendliness' can only go so far in addressing the stigma related to dementia and a focus on the rights of people living with dementia and the extent to which formal support is funded and provided is needed as well (Alzheimer's Disease International 2019). There are aspects of the concept of citizenship and its application to dementia that are not straightforward and still to be resolved (Bartlett and O'Connor 2010). However, a social citizenship approach can be seen as a way forward in research and practice to raise the status of people living with dementia in society, so that a visible positive image of people living with dementia may encourage discussion about dementia and facilitate help seeking for a diagnosis. The use of citizenship as a lens to consider the role of carers is also desirable, as the extent to which carers are able to participate in society as full citizens, particularly if they have to give up work to care for their loved ones, is debatable (Singleton and Fry 2015). In the same way that positive images of people living with dementia in society are needed to reduce stigma, positive images of carers being supported and accorded status within society are needed. These images may help carers to feel that help seeking for a diagnosis of dementia will be of benefit to them as well as the person they care for.

9.6.3 Development of tools to support discussion about dementia

A key aspect of the concept of help seeking is a willingness to disclose and share concerns with another person (Cornally and McCarthy 2011). In 2013 the Department of Health in England stated that they wished, "to create a society where anyone who thinks they may have dementia can speak openly about it, facilitating access to a diagnosis and appropriate post-diagnosis support" (Department of Health, 2013:35). However, the findings of this study have supported earlier work demonstrating that stigma prevents discussion about dementia between people living with dementia and carers and between carers and health care professionals (Department of Health, 2009). In addition to the initiatives described above aimed at reducing stigma, tools to support carers to raise and discuss their concerns with their loved one and with health care professionals would be helpful. The Alzheimer's Society (2020b) in the UK has resources for people who are worried about their memory and advice

for people concerned about someone else's memory including planning a conversation to discuss concerns. An internet resource from the USA includes examples of questions to use to start a conversation, in addition to other tips (Sauer 2018). It is possible that tools containing more detail such as this, may give carers more confidence to discuss their concerns. The use of a video including people living with dementia, carers and health care professionals talking about the experience of attending a memory clinic for assessment, received positive feedback as being reassuring and increasing confidence and understanding in people who were awaiting an appointment (Baruch et al 2017). Providing information and an opportunity to discuss concerns at the pace of the person living with dementia and their carer, could enable people to make informed choices about seeking help at the right time for them.

Studies focused on the care of people living with dementia in the acute hospital setting reveal a lack of confidence and skill amongst health care staff in communicating with people living with dementia (Turner et al 2017) and it is possible that this extends to discussing concerns about a possible dementia diagnosis. Gove et al (2017) suggested that tools for GPs to help facilitate conversations about dementia, that considered stigma as a reason why people may not want a diagnosis, could be helpful in encouraging timely diagnosis. A tool designed to help staff in care home settings talk about dying with the relatives of people with advanced dementia increased staff confidence and knowledge, and discussions moved from being reactive to a structured dialogue in which relatives felt engaged and confident in discussing their loved ones wishes and making decisions (Stirling et al 2014). A tool for discussing concerns about dementia, such as that developed by Stirling et al (2014) which aims to inform staff, provide a process and examples of what to say, may be helpful for health care professionals, particularly those in primary care, including community nurses, to use when they suspect a person may be experiencing early signs of dementia.

Future research, involving people living with dementia who have been diagnosed, could explore what worked for them when family members and health care professionals talked to them about their concerns or how they would have preferred someone to approach them about it. The development of discussion tools to support carers and health care professionals could then be piloted to determine whether this increases confidence and a willingness to share concerns with the person living with dementia, and the acceptability of the approach to people living with dementia.

9.7 Concluding statement

This mixed methods study aimed to understand what prevents help seeking for diagnosis of dementia. It has been proposed that stigma related to dementia and the threat this posed to independence and autonomy could prevent help seeking when the carer's social network ties shared these views and the carer was unable to share their concerns with others. The findings of the study have contributed to the body of evidence on help seeking for a dementia diagnosis, and the implications of these for a timely diagnosis of dementia have been considered. An increased focus on dementia friendly communities and a social citizenship approach to dementia are an opportunity to address the stigma associated with dementia and provide positive images of people living with dementia in society. Tools to support carers and health care professionals to discuss their concerns about dementia with family members and patients, may help to reduce myths and stigma related to dementia, and encourage people living with dementia to make decisions about when and how to seek help for a diagnosis, at a time that is right for them.

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