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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

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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" with the intention of disclosing a problem in exchange for help (Cornally and McCarthy, 2011:286). 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 (Table 1).

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 the supplementary material.

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 the supplementary material.

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 1).

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 2. The perspective of carers were reported in 24 studies and the perspective of carers and PLWD in 8 studies (see Table 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. 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.

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 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 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 seeking 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, 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, 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. 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.

11. Conflict of interest

None

12. Description of Authors roles

All authors contributed to the conception and design of the review. MP carried out searches and MP, SB, JH, LA independently reviewed and selected studies for inclusion along with quality appraisal. MP extracted the data with checking by JH and SB. Initial synthesis of data was by MP with refining of synthesis by all authors. Drafting of manuscript for publication was by MP with critical revising of the manuscript by all authors. All authors approved final version for publication.

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Figure 1 PRISMA flow chart

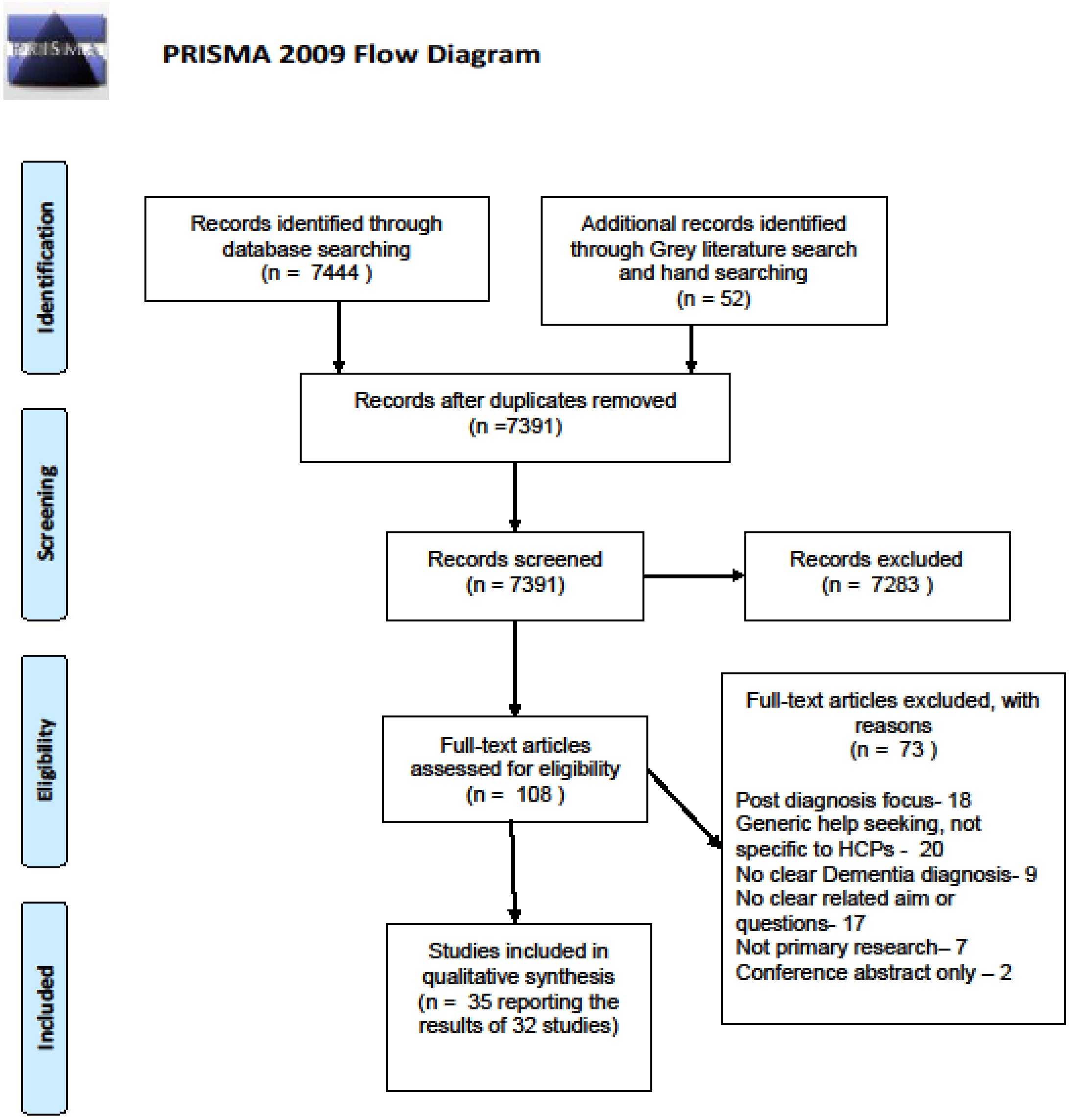

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Table 1 Eligibility Criteria

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.

Table 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)	Description of factors associated with delay in	1480 carers	Quantitative - mail survey	Barriers: unsure of severity, normal ageing, difficult to raise

US	diagnosis of Alzheimer's disease	52.4% female; Mean age 58yrs 88% White 100% AD diagnosis		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 diagnosis of dementia for their loved ones	7 carers 71.4%female Aged 53-71yrs All African American	Qualitative – focus group	Barriers: knowledge deficit, normalising symptoms and attributing them to ageing, respect for the PLWD. 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	11 carers 81.8% female , Average age 50yrs	Qualitative - Semi structured interviews	Barriers: denial and a failure to recognise symptoms due to lack of knowledge about dementia.

	sample of Latino caregivers	All Latino – Colombian, Puerto Rican, Argentinian, Guatemalan, Cuban, Dominican		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 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	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

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 illness and ends with the diagnosis).	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 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 carers to help-seeking for dementia symptoms	18 carers 72.2%female Aged 27-85yrs, mean 57yrs 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	Qualitative – semi-structured interviews	Barriers: delaying until symptoms were unmanageable, attribution of symptoms to other causes, delays due to PLWD, different cultural 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	3 PLWD and 12 carers PLWD: 33.3%female	Qualitative – focus groups and	Barriers: stigma, normalisation of symptoms and lack of awareness of signs and symptoms.

	review of qualitative studies looking at patient and carer experiences of diagnosis and treatment of dementia	Carers: 58.3%female	one to one interviews	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-structured interviews	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
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 interviews	Barriers: stigma, perceptions and beliefs of dementia in the community, fear, cost, normal ageing Facilitators: knowledge of dementia, recognition of symptoms, key incident

Table 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 (2011)	▨	▨	▨	▨	▨		▨	▨			▨		
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)	▨	▨									▨		▨

Table 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,**	**Sampling strategy relevant to answer**	**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**	**Components adhere to quality criteria of each**
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 (2011)	✓	✓	?	✓	✓										
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[17]: ✓= Yes, X = No, ? = can't tell															