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Primary Care Physicians' Perceived Barriers to Optimal Dementia Care: A Systematic Review

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Key points:

- A range of patient, provider and system barriers to optimal dementia care in primary care have been identified.
- Future research should utilise theory-driven approaches to identifying barriers to diagnosis and management of dementia in primary care.

Abstract

Background and Objectives

Primary care physicians (PCPs) have a key role in providing care for people with dementia and their carers, however a range of barriers prevent them from delivering optimal care. We reviewed studies on PCPs' perceptions of barriers to providing optimal dementia care, including their methodological quality, whether they focused on barriers related to diagnosis and/or management, and the patient- provider- and system-level barriers identified.

Research Design and Methods

Studies were included if they were quantitative studies published since 2006 which reported on PCPs' perceptions of the barriers to providing dementia care. The methodological quality of identified studies was assessed using an adapted version of accepted rating criteria for quantitative studies. Data were extracted from studies which were rated as 'moderate' or 'strong' quality.

Results

A total of 20 studies were identified, sixteen of which were rated as 'moderate' or 'strong' methodological quality. Patient-related barriers included a reluctance to acknowledge cognitive decline, and patient non-adherence to management plans. Provider-related barriers included a lack of training and confidence. System-related barriers included a lack of time during consultations, and lack of support services.

Discussion and Implications

This review highlights a range of barriers to dementia diagnosis and management from studies rated as being methodologically adequate. Future studies should also utilise theory-driven approaches to exploring a comprehensive range of barriers to optimal dementia care across the care trajectory.

Key words

Primary care, Alzheimer's disease, quality of care, Analysis - Systematic Review

Background and Objectives

Primary Care Physicians Play an Important Role in Identifying and Managing Dementia

Worldwide, dementia is estimated to affect almost 50 million people, and this is predicted to more than double by 2050 (Prince et al., 2015), placing significant pressure on health care systems (Sivananthan, Puyat, & McGrail, 2013). Primary care physicians (PCPs; also known as general practitioners, family physicians, or internists) have a central role to play in dementia care given they are often the first point of contact with the health care system for people with dementia (Boustani, Schubert, & Sennour, 2007). The PCP's role in dementia care encompasses assessment and diagnosis, including referral to specialists where necessary, and management of dementia, which involves providing information about disease progression and accessing local support services, collaborative care planning, ongoing monitoring, and providing support to carers (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012; Sivananthan et al., 2013).

A Range of Barriers May Prevent Primary Care Physicians from Providing Optimal Care to People with Dementia

Primary care for people with dementia and their carers is often sub-optimal, characterised by low rates of detection of dementia, poor communication and low satisfaction with care (Bridges-Webb, Wolk, Britt, & Pond, 2003; Hinton et al., 2007). Some of the identified barriers are generic to the delivery of optimal care, such as a lack of time, lack of confidence or appropriate training, and inadequate reimbursement systems (Aminzadeh et al., 2012; Koch & Iliffe, 2010). Other identified barriers are more specific to the context of dementia care and include difficulties distinguishing between normal signs of aging and

dementia, concerns about disclosing a diagnosis due to the associated stigma, and perceptions about a lack of therapeutic benefits of early diagnosis and treatment (Aminzadeh et al., 2012; Koch & Iliffe, 2010). Much of the research conducted on PCPs' perceived barriers has been qualitative (Koch & Iliffe, 2010). While such qualitative work is important in identifying the likely barriers to optimal care, quantitative research is needed in order to understand the relative importance of identified barriers. Identifying the most prevalent barriers will assist in informing intervention strategies which have a high likelihood of improving quality of dementia care.

Methodologically Rigorous and Comprehensive Research to Accurately Identify Barriers is Needed

To ensure that studies accurately and comprehensively identify the most significant barriers experienced by PCPs, only those studies that meet acceptable methodological quality should be considered. Reliable and accepted criteria are available to assess methodological quality of quantitative studies (Thomas, Ciliska, Dobbins, & Micucci, 2004). Examining the quality of research will highlight possible difficulties with conducting research in this area, or identify whether there is a need to increase the capacity or skills of researchers in this area. In addition to methodological rigour, studies should aim to identify barriers across the full trajectory of dementia care, including both dementia diagnosis and management. Identifying barriers across these phases has potential to optimise care for people with dementia through all stages of the disease trajectory.

While three previous reviews have examined PCPs' perceived barriers to the delivery of optimal dementia care (Aminzadeh et al., 2012; Bradford, Kunik, Schulz, Williams, & Singh, 2009; Koch & Iliffe, 2010), two of these did not systematically examine the frequency of

reporting of barriers to optimal dementia care, while none considered the methodological quality of the studies reviewed. Therefore, the current review aimed to examine quantitative data-based studies reporting on PCPs' perceptions of barriers to providing optimal care to people with dementia and/or their carers, including:

- 1) The methodological quality of these studies, assessed using an adapted version of the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004), which has been endorsed in the Guidelines for Systematic Reviews in Health Promotion and Public Health;
- 2) For those studies which are rated either 'strong' or 'moderate' methodological quality, whether the study: a) focused on diagnosis and/or management of dementia, and b) the patient, provider, and system-related factors which have been reported by PCPs as being barriers to the provision of optimal care.

Research Design and Methods

Literature Search

Medline, Embase, PsycInfo, Cochrane Library and CINAHL databases were searched using a combination of Medical Subject Headings (MeSH) and key words (see Supplementary File 1). The main themes included in the search were 'primary care physician' (including interchangeable terms such as 'general practitioner' and 'primary care provider'), 'dementia or Alzheimer's disease', and 'barriers' (including related terms 'attitudes' and 'practice patterns'), which were combined using AND. Searches were limited to English language studies published from January 2006 to July 2016. Only studies published since 2006 were considered to coincide with the release of the National Institute for Health and Care Excellence (NICE) dementia care guidelines, which provide comprehensive recommendations across the disease trajectory (National Institute for Health and Care

Excellence, 2006). While other guidelines were published prior to 2006 for England and Scotland (Eccles, Clarke, Livingston, Freemantle, & Mason, 1998; Scottish Intercollegiate Guideline Network (SIGN), 1998), the release of the NICE guidelines was selected given their coverage of the entire UK. The reference lists of all included studies were manually searched to identify any further relevant articles.

Inclusion/Exclusion Criteria

Studies were included if they: a) reported on PCPs' perceptions of the barriers to providing care to people with dementia and/or their carers; b) were quantitative studies, or quantitative data was reported separately if using a mixed methodology; c) had been published since 2006; d) were conducted in an OECD high income country (NationMaster, 2017); e) reported PCPs' views separately in a mixed sample of health care providers, or PCPs comprised at least 80% of the mixed sample; f) reported PCPs views on dementia separately when examining barriers to providing care for multiple diseases; and g) were published in English. Primary care physicians were defined as community-based physicians providing whole person care to individuals, and included general practitioners, family physicians and community-based internists). Physicians specialising in geriatrics or psychiatry were excluded. Only high income OECD countries were included, to allow for comparison of barriers across relatively similar health care systems. Studies were excluded if they were: a) not data-based (i.e. case studies, commentaries, protocols, editorials or conference abstracts) or b) intervention or measure development studies.

Article Screening

All article titles and abstracts were screened for eligibility by one author (NN). 10% of titles/abstracts and 20% of full-text articles were randomly selected and assessed by a

second author (EM) to determine inter-rater reliability of article coding. Any discrepancies in coding between authors were resolved via discussion.

Methodological Quality

The quality of quantitative studies was evaluated using an adapted version of the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004). This tool was selected as it has been endorsed in the Guidelines for Systematic Reviews in Health Promotion and Public Health, which were developed to support systematic reviews conducted within the Cochrane Collaboration (Armstrong, Waters, & Jackson, 2007). Although this tool is applicable for rating both intervention and descriptive studies, only those criteria relevant to descriptive studies were applied. Table 1 summarises the criteria used to assess the methodological quality of the studies. This included: i) selection bias (representativeness of the sample; response rate); and ii) data collection methods (were data collection tools shown to be valid/reliable?). Each quality criteria is rated as ‘strong’, ‘moderate’ or ‘weak’ based on provided guidelines. As this tool does not take account of sample size, which is crucial to the accuracy of prevalence estimates, we added an additional ‘sample size’ criterion, adapted from another commonly used rating scale (Fowkes & Fulton, 1991). This included consideration of whether a justification for the sample size was reported by the authors (for example, a power calculation was included), and whether the sample size was adequate to give an acceptable level of precision. An acceptable level of precision was set at 10%. Assuming a prevalence rate of 50% and 95% level of confidence (Naing, Winn, & Rusli, 2006), a sample size of $n = 96$ or more was considered to be adequate. Following the EPHPP Quality Assessment Tool for Quantitative Studies guidelines, each paper was then given a global rating of ‘strong’ (no ‘weak’ ratings across quality components); ‘moderate’ (one ‘weak’ rating across quality components), or ‘weak’ (two or more ‘weak’ ratings across quality components).

Data Extraction

For each study receiving an overall methodological quality rating of ‘moderate’ or ‘strong’, the barriers reported by PCPs to the provision of optimal care were extracted. Results from studies with a ‘strong’ or ‘moderate’ rating are reported as these are the most likely to be generalisable, valid, and have an adequate level of precision. Barriers in relation to each phase of care (diagnosis or management) were extracted. For studies which asked respondents about barriers across the care trajectory, barriers which applied to both phases of care were coded in their respective categories (diagnosis, management), and also coded as ‘general barriers to diagnosis and management’. Barriers within each of these aspects of care were coded as: i) patient-related barriers (e.g. patient knowledge or attitudes); ii) provider-related barriers (e.g. provider skills, knowledge); or iii) structural/system barriers (e.g. policies, funding or infrastructure). The studies reporting each barrier, proportions of participants endorsing each barrier (where available), and the countries and years in which the barrier was reported were extracted.

Results

An overview of the article screening process following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) four-phase flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) is shown in Figure 1. The search identified 537 studies, of which 20 met the criteria for inclusion in the review (with two studies using the same dataset). Agreement between the two raters was excellent for the title and abstract screen (94% agreement, kappa=0.74, n=54); and for the full text screen (90% agreement, kappa=0.80, n=10) against inclusion criteria (Fleiss, 1981).

Methodological Quality of Studies

Table 2 shows the methodological quality assessment for included studies. Five of the 20 included studies were rated overall as ‘strong’, 11 studies were rated as ‘moderate’, and four were rated as ‘weak’. The criterion which was most likely to receive lower quality ratings was ‘selection bias’. Thirteen studies received a ‘weak’ rating on this criterion, while seven received a ‘moderate’ rating. ‘Weak’ ratings on this criterion were mainly due to poor response rates (<60%). For ‘data collection methods’, most studies received either a ‘moderate’ (n=13) or ‘strong’ (n=1) rating. The majority of studies provided evidence for the validity of the data collection tools (which included face or content validity), but did not provide evidence for their reliability. All studies received either a ‘moderate’ (n=17) or ‘strong’ (n=3) rating for the ‘sample size’ criterion. The majority of studies had an adequately powered sample but did not provide a justification for the selected sample size.

Characteristics of Studies Meeting Minimum Methodological Criteria

Data extracted from the 16 studies which were rated as either methodologically ‘strong’ or ‘moderate’ are reported in Supplementary File 2. Four of these studies were conducted in the USA (Baloch, Moss, Nair, & Tingle, 2010; Fortinsky, Zlateva, Delaney, & Kleppinger, 2010; Harris, Chodosh, Vassar, Vickrey, & Shapiro, 2009; Stewart et al., 2014), three in the UK (Brazil, Carter, Galway, Watson, & van der Steen, 2015; Fox et al., 2014; Russ, Calvert, & Morling, 2013), three in Germany (Kaduszkiewicz, Bachmann, & van den Bussche, 2008a; Kaduszkiewicz, Wiese, & van den Bussche, 2008b; Thyrian & Hoffmann, 2012), and two each in Canada (Hillmer, Krahn, Hillmer, Pariser, & Naglie, 2006; Moorhouse, Hamilton, Fisher, & Rockwood, 2011), France (Cantegreil-Kallen, Turbelin,

Angel, Flahault, & Rigaud, 2006; Somme, Gautier, Pin, & Corvol, 2013) and Ireland (Cahill et al., 2008; Cahill, Clark, Walsh, O'Connell, & Lawlor, 2006).

Stage of dementia care trajectory. Three studies focused only on barriers related to the diagnosis of dementia (Cahill et al., 2008; Cahill et al., 2006), including one study specifically looking at barriers to the disclosure of a diagnosis of dementia (Kaduszkiewicz et al., 2008a). Seven studies focused only on management of dementia (Brazil et al., 2015; Cantegreil-Kallen et al., 2006; Fortinsky et al., 2010; Hillmer et al., 2006; Moorhouse et al., 2011; Russ et al., 2013; Somme et al., 2013). A number of these examined only very specific aspects of dementia management, such as the provision of psychosocial support (Cantegreil-Kallen et al., 2006), prescribing medications (Hillmer et al., 2006), assessing fitness to drive (Moorhouse et al., 2011), shared care (Russ et al., 2013), and advanced care planning (Brazil et al., 2015). Six studies examined the dementia care trajectory including both diagnosis and management (Baloch et al., 2010; Fox et al., 2014; Harris et al., 2009; Kaduszkiewicz et al., 2008b; Stewart et al., 2014; Thyrian & Hoffmann, 2012).

Perceived Barriers in Studies Meeting Minimum Methodological Criteria

Barriers related to dementia diagnosis

Patient-related barriers. Patient-related barriers associated with diagnosis of dementia were identified in four studies (Brazil et al., 2015; Cahill et al., 2008; Cahill et al., 2006; Fox et al., 2014; Kaduszkiewicz et al., 2008a). Barriers reported varied across studies, and included concerns about the patient's ability to comprehend the diagnosis (38%)(Cahill et al., 2006), patient reluctance to acknowledge cognitive decline (61%)(Kaduszkiewicz et al., 2008a), and patients feeling ashamed of cognitive decline (75%)(Kaduszkiewicz et al., 2008a).

Provider-related barriers. Lack of knowledge or training was a commonly reported barrier by 10-63% of respondents across seven studies (Baloch et al., 2010; Cahill et al., 2008; Cahill et al., 2006; Fox et al., 2014; Kaduszkiewicz et al., 2008b; Russ et al., 2013; Somme et al., 2013). A lack of confidence or comfort with diagnosis was also reported by between 23-66% of respondents in four studies (Baloch et al., 2010; Cahill et al., 2008; Cahill et al., 2006; Thyrian & Hoffmann, 2012). A lack of perceived benefits associated with early diagnosis was less commonly reported, by 15-30% of respondents across four studies (Cahill et al., 2008; Fox et al., 2014; Kaduszkiewicz et al., 2008a; Kaduszkiewicz et al., 2008b).

System-related barriers. A range of system barriers to optimal diagnosis were reported. One of the most commonly reported system barriers was a lack of time, which was reported across four studies by 41-86% of respondents (Cahill et al., 2008; Fortinsky et al., 2010; Stewart et al., 2014; Thyrian & Hoffmann, 2012). Lack of access to specialist services or support for those diagnosed was also commonly reported, by 20-59% of respondents across four studies (Cahill et al., 2008; Fortinsky et al., 2010; Fox et al., 2014; Stewart et al., 2014). Between 56-91% identified the need for national guidelines for screening and diagnosis, although this was reported in two studies only (Baloch et al., 2010; Kaduszkiewicz et al., 2008b). Only one study identified the need for better screening and diagnostic tools, with 40 and 48% of respondents respectively identifying this as a barrier (Stewart et al., 2014).

Barriers related to dementia management

Patient-related barriers. Patient-related barriers were identified in four studies examining specific aspects of dementia management. Non-compliance with care was reported by 19-54% of respondents for nursing and psychosocial care (Cantegreil-Kallen et al., 2006), while 72% of respondents identified non-compliance with medications (Hillmer et al., 2006).

A lack of support from carers was cited in relation to assessing fitness to drive (27% of respondents)(Moorhouse et al., 2011) and planning psychosocial support (66% of respondents)(Cantegreil-Kallen et al., 2006). Other barriers reported by a substantial proportion of respondents included fear of damaging the physician-patient relationship (43%) (Moorhouse et al., 2011), or increasing anxiety by informing families about prognosis (56%) (Brazil et al., 2015).

Provider-related barriers. A range of provider-related barriers were reported across 12 studies. Negative perceptions or a perceived lack of benefit in managing dementia were identified by 11-77% of respondents across four studies (Brazil et al., 2015; Harris et al., 2009; Kaduszkiewicz et al., 2008b; Somme et al., 2013). A general lack of knowledge or training in relation to management was reported by 5-66% of respondents in five studies (Baloch et al., 2010; Cantegreil-Kallen et al., 2006; Kaduszkiewicz et al., 2008b; Moorhouse et al., 2011; Thyrian & Hoffmann, 2012). Lack of knowledge or training specifically related to non-pharmacological and pharmacological management of dementia symptoms was reported by 10-48% of respondents in three studies (Fortinsky et al., 2010; Hillmer et al., 2006; Somme et al., 2013). Between 20-50% identified a lack of training in communicating with people with dementia and their families across two studies (Kaduszkiewicz et al., 2008b; Somme et al., 2013). Between 14-40% of respondents in three studies indicated they were not confident or comfortable managing dementia across three studies (Fox et al., 2014; Moorhouse et al., 2011; Somme et al., 2013). Across five studies, 10-56% identified lack of knowledge about community or support services (Cantegreil-Kallen et al., 2006; Fortinsky et al., 2010; Fox et al., 2014; Russ et al., 2013; Somme et al., 2013). In one recent study (Brazil et al., 2015), 80% of respondents identified a lack of knowledge about involving families in end of life care.

System-related barriers. A range of system-related barriers to management were identified. A lack of time was reported as a barrier to management of dementia by 41-86% of respondents in three studies (Fortinsky et al., 2010; Stewart et al., 2014; Thyrian & Hoffmann, 2012). A lack of available support services or resources was also reported by 11-72% of respondents across seven studies (Cantegreil-Kallen et al., 2006; Fortinsky et al., 2010; Harris et al., 2009; Moorhouse et al., 2011; Russ et al., 2013; Stewart et al., 2014; Thyrian & Hoffmann, 2012). Difficulties in collaboration and care coordination with other care providers was reported by 4-70% of respondents across five studies (Cantegreil-Kallen et al., 2006; Harris et al., 2009; Russ et al., 2013; Somme et al., 2013; Thyrian & Hoffmann, 2012). Three studies also reported financial problems encountered by families as being barriers to management (16-45% of respondents) (Cantegreil-Kallen et al., 2006; Stewart et al., 2014; Thyrian & Hoffman, 2012).

Barriers related to both dementia diagnosis and management. Four studies identified barriers that applied generally to both diagnosis and management of dementia. The only general provider-related barrier was lack of training (63%; Baloch et al., 2010). Echoing the findings from the aforementioned studies, these studies reported a number of general system-related barriers, including a lack of time, reported by 78-86% of respondents in two studies (Stewart et al., 2014; Thyrian & Hoffmann, 2012) and the need for guidelines, reported by 56% of respondents in one study (Kaduszkiewicz et al., 2008b). Other system-related barriers common to diagnosis and management included lack of access to community resources and specialists, reported by 20% of respondents (Stewart et al., 2014), poor coordination with care providers, lack of community education, and inadequate reimbursement, reported by 70-82% of respondents (Thyrian & Hoffmann, 2012).

Time period and countries in which barriers were reported. Most barriers were reported consistently over time since 2006, with the exception of the patient-related barriers

to diagnosis, which were mostly reported prior to 2008. Most of the patient-related barriers (in relation to either diagnosis or management) were only reported for one or two countries, including perceived stigma/embarrassment (Ireland, Germany), or lack of support from carers (Canada, France). However, concerns about the impact of a diagnosis on the patient was reported in studies from Ireland, the UK and Canada. In contrast, three provider-related barriers were reported across all or most of the countries in which the included studies were conducted. A lack of training or knowledge, and lack of provider confidence or comfort, were reported by studies from all included countries, while negative perceptions or perceived lack of benefit of diagnosis or management was reported in all countries except Canada. Some system-level barriers were reported across a range of countries, including a lack of support or specialist services (all countries), lack of time (Germany, Ireland and the USA), and poor care coordination (Germany, France, the UK and USA). Other system barriers were only reported in 1-2 countries, such as lack of treatment options (USA), inadequate financial reimbursement (USA and Germany) and potential for liability (Canada).

Discussion and Implications

PCPs play a central role in the identification and management of dementia, yet a range of barriers prevent the delivery of optimal dementia care in primary care. This review identified 16 quantitative studies of ‘strong’ or ‘moderate’ methodological quality exploring PCP perceptions of barriers to the delivery of optimal dementia care, which have been published since the release of the earliest comprehensive guidelines for dementia care.

Methodological Quality of Included Studies

In general, the methodological quality of studies was adequate. One quarter of studies met all methodological quality criteria and were rated as ‘strong’, and just over half (11/20) were rated of ‘moderate’ quality. A common identified methodological weakness was low or unreported response rates; eleven studies had a response rate of less than 60% and three studies did not report their response rate at all. Low response rates may reflect lack of capacity or willingness of PCPs to participate in research. Future research in this area should consider using strategies shown to increase response rates among clinicians, such as use of financial incentives, personalised invitations, and involvement of a medical peer (VanGeest, Johnson, & Welch, 2007). Another common methodological issue was the failure to include a justification for the sample size. Reporting guidelines such as Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)(Von Elm et al., 2014) specify that an explanation of the sample size should be included in the reporting of the study to ensure that the planned sample size is appropriate for the types of analyses conducted. Finally, there was a lack of methodologically rigorous measures used to assess barriers. While fourteen studies used a measure which had evidence of at least face validity, only one measure had any evidence of reliability. This reflects the lack of available methodologically rigorous tools for the assessment of barriers to the provision of dementia care. Such measures are needed to ensure accurate and reliable estimation of the prevalence of perceived barriers.

Primary care physicians’ Perceptions of the Barriers to Providing Optimal Care

In relation to the diagnosis of dementia, a range of patient-related barriers were reported, the most common of which were a perceived reluctance by patients to acknowledge cognitive decline, or a perception that patients were ashamed of cognitive decline. However, it is not clear whether these concerns reflect actual patient/carer attitudes, or rather PCPs’

perceptions of patient attitudes towards diagnosis or cognitive decline. Findings highlight the importance of adopting a patient-centred model of dementia care, in which the patient is asked about their preferences for receiving diagnostic information. Patient-centred consultation styles and communication training for health professionals have been demonstrated to improve the patient experience of health care (Australian Commission on Safety and Quality in Health Care, 2010). In line with this approach, there has been a recent shift from advocating for an ‘early’ diagnosis to a more patient-centred ‘timely’ diagnosis, which refers to delivery of a diagnosis at the most appropriate time for the individual, taking into consideration their circumstances and values. Therefore future studies should move towards identifying barriers to a patient-centred timely diagnosis, as opposed to an ‘early’ diagnosis. In relation to management of dementia, one of the key patient-related barriers was non-adherence to treatment or management plans. This may be overcome by exploring self-management strategies involving the carer or other family to ensure adherence to treatment plans.

The most commonly reported provider-related barriers to the diagnosis of dementia were a lack of training and lack of confidence or comfort with diagnosis. Less commonly reported was a lack of perceived benefits associated with early detection or diagnosis. Similarly, a lack of knowledge or training and lack of confidence were frequently reported provider-related barriers to the management of dementia, and a lack of training was reported as a general barrier to diagnosis and management. The perceived lack of training suggests that educational interventions may be effective in addressing this barrier. A systematic review (Perry et al., 2011) showed that educational interventions for PCPs may be somewhat effective in improving detection of dementia, especially where the PCP is actively involved in the intervention, but that educational interventions do not appear to increase adherence to dementia guidelines. These findings suggest that overcoming this barrier alone may be

insufficient to improve quality of care. A range of system-related barriers were reported across dementia diagnosis and management. Clinician time was reported as a barrier to both dementia diagnosis and management. This barrier may be overcome by system-level changes to allow the assessment of patient needs prior to appointments. For example, it might be possible for practice nurses to conduct pre-consultation needs assessments. Alternatively, self-or carer-reported online needs assessment tools (Cherbuin, Anstey, & Lipnicki, 2008; Waller et al., 2015) could be completed in waiting rooms on an electronic touch screen device, or at home on a personal computer. In this way PCP consultation time could be used more efficiently to focus on delivering strategies to address identified needs. A lack of access to specialist and other support services was also identified as a system-related barrier to both dementia diagnosis and management. Previous qualitative work suggests that this barrier may be due, at least in part, to low awareness among PCPs about available community and support services (Iliffe & Wilcock, 2005; Yaffe, Orzeck, & Barylak, 2008). Providing PCPs with knowledge about available resources and how to access these may go at least some way to overcoming this barrier. Additional strategies to overcome a lack of access to services might include referral to telephone or online support to supplement care provision (Glueckauf, Ketterson, Loomis, & Dages, 2004; Winter & Gitlin, 2007).

Most types of barriers were reported consistently across the 10 year time period analysed, suggesting that the same barriers have remained over time. However, the relatively small number of studies, combined with the fact that most studies (n=9) were published in the first half of the time range analysed may have precluded the identification of any changes to barriers over time.

When examining differences by country, both provider and system-related barriers (across either diagnosis or management) were more likely to be reported across a range of countries, than were patient-related barriers. This suggests that patient-related barriers may be

influenced by context-specific beliefs and attitudes regarding dementia. In contrast, provider barriers including a lack of training, lack of confidence/comfort, and negative perceptions about dementia care; and system barriers, including a lack of support services, poor care coordination, and lack of time were reported across all or most of the countries included in this review, suggesting that these issues are pervasive globally. However, these findings should be interpreted with caution given the relatively limited number of countries in which studies were published.

The ability to reliably determine the relative importance of the barriers identified in this review is hampered by the small number of studies identified, and wide ranges in the proportions of respondents endorsing each barrier. The latter may be partially due to heterogeneity across study samples, as well as a lack of consistency in items used to assess barriers across studies. For example, some studies asked about specific aspects of care (e.g. lack of comfort in decision making regarding fitness to drive)(Moorhouse et al., 2011), while others asked about more general aspects (lack of comfort in their role in managing dementia)(Somme et al., 2013). Ensuring generalisability of samples, and development of more standardised and comprehensive measures to assess barriers may assist in reducing this variability and producing more accurate prevalence estimates.

Future Directions

Identifying barriers to adherence to optimal care guidelines. Before effective interventions can be developed, there is a need for increased, high quality research effort to be directed towards understanding the barriers that PCPs' perceive to providing optimal dementia care. Across all studies identified in this review, a variety of measures for exploring PCP barriers to care were used, with only a minority exploring adherence to established guidelines for dementia care. Clinical guidelines aim to represent best practice care according

to the available evidence (Rosenfeld, Shiffman, & Robertson, 2013), and therefore should be used as a benchmark against which current practice is assessed. Measuring barriers to adherence to specific guidelines will provide more consistency in assessing the prevalence of barriers across studies, improve knowledge about the reasons why specific recommendations are not implemented, and assist in efforts to improve guideline implementation. An updated version of the NICE dementia care guidelines is currently in development. Upon release of these updated guidelines it may be timely to develop measures to assess guideline adherence.

Barriers across the dementia care pathway. To improve the quality of care delivered to people with dementia, gaps in care across all phases of the dementia care pathway should be identified and addressed. Identifying and addressing barriers which are common to both diagnosis and management of dementia has significant potential to have positive impacts on outcomes for a large number of people with dementia. However, attempting to identify the barriers which are common across the pathway based on studies which have looked at only individual phases of care is limited by heterogeneity in study methodology and sample characteristics. Only six of the included studies (Baloch et al., 2010; Fox et al., 2014; Harris et al., 2009; Kaduszkiewicz et al., 2008b; Stewart et al., 2014; Thyrian & Hoffmann, 2012) focused on barriers across both diagnosis and management of dementia. Studies that identify the barriers which, if addressed, would be likely to improve care across the entire trajectory will be beneficial in prioritising which barriers can and should be addressed.

Theory-driven exploration of barriers. Given the widely accepted role of theory in informing efforts to implement guideline-recommended care (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005), theoretical frameworks should be used to establish the determinants of adoption. However, none of the 16 studies included in this review made use of theory for exploring the barriers associated with the provision of optimal dementia care in primary care

settings. This finding accords with a recent review (Liang et al., 2017) which showed that only half of studies which explored guideline implementation strategies were based on theory. Of these, most did not explain how they employed theories in the planning or evaluation of guideline implementation. Future studies should therefore use theory to map barriers which are likely to determine uptake of guideline-recommended care. For example, theoretical frameworks which specify classes of determinants that influence implementation outcomes may be useful. The Theoretical Domains Framework aims to identify the factors which influence the uptake of evidence-based interventions, using a synthesis of psychological theories. The framework includes 14 domains: 1) knowledge, 2) skills, 3) social/professional role and identity, 4) beliefs about capabilities, 5) optimism, 6) beliefs about consequences, 7) reinforcement, 8) intentions, 9) goals, 10) memory, attention, and decision processes, 11) environment context and resources, 12) social influences, 13) emotion, and 14) behavioural regulation (Cane, O'Connor, & Michie, 2012). Other frameworks consider the broader interrelationships between the understanding of evidence to be adopted, ability of the context to cope with change, and facilitation needed to ensure adoption (Kitson, Harvey, & McCormack, 1998). While mapping barriers to theoretical frameworks is important for establishing the determinants of adoption of best evidence care, studies also need to test which theoretical frameworks are likely to produce behaviour change. Well-controlled intervention studies which manipulate components of theoretical frameworks are needed to produce high level evidence for which theories increase the probability of adherence to optimal care.

Integration of quantitative with qualitative data. This review did not include qualitative studies on this topic (e.g.(Allen et al., 2005; Hinton et al., 2007)). While qualitative studies are unable to provide robust prevalence estimates, they may provide a more in-depth understanding of barriers. Qualitative interviews may also more effectively

capture the complexities PCPs face in dementia diagnosis and management, such as the interplay of individual and situational factors which contribute to timing of diagnosis disclosure. Therefore, a valuable approach may be to integrate findings of reviews of qualitative and quantitative studies, to further inform the development of interventions to overcome barriers.

Limitations

This review includes only articles published in peer reviewed journals. Although it is likely that other articles exist outside of these sources, it is unlikely that these articles would be of adequate methodological quality. Studies not published in English were excluded, limiting our ability to examine differences between countries in PCPs' perceptions of barriers.

Conclusions

This review identified patient, provider and system-level barriers across both diagnosis and management phases of primary dementia care, which were reported in studies rated as having adequate methodological quality. Focusing on data generated from studies which use robust methodology ensures the findings can be relied upon, and consequently increases the likelihood that interventions informed by such data are effective. The relatively low number of studies and methodological inconsistencies across studies precluded accurate identification of the relative importance of different types of barriers. Some of the key methodological flaws which should be remedied in future research include the need to comprehensively examine barriers to aspects of dementia care across the entire care pathway,

utilise theory in the approach to the exploration of barriers, and develop robust measurement tools for this purpose.

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Table 1: Summary of the methodological quality criteria and scoring system used to assess studies included in the review

Quality component	Assessment and response items	Component rating scale
Selection bias	Q1. Representative sample	Strong: Q1=1 and Q2=1
	1. Very likely	
	2. Somewhat likely	Moderate: Q1=1 or 2 and Q2=1 or 2 or 5
	3. Not likely	
	4. Can't tell	Weak: Q1=3; or Q2=3; or Q1=4 and Q2=5
	Q2. Response rate	
	1. 80-100%	
	2. 60-79%	
	3. <60%	
	4. Not applicable	
	5. Can't tell	
Data collection methods	Q3. Data collection tools valid	Strong: Q3 = 1 and Q4 = 1
	1. Yes	
	2. No	Moderate: Q3=1 and Q4=2 or 3
	3. Can't tell	
	Q4. Data collection tools reliable	Weak: Q3=2; or Q3=3 and Q4=3
	1. Yes	
	2. No	
	3. Can't tell	
Sample size justification	Q5. Justification for sample size reported	Strong: Q5=1 and Q6=1
	1. Yes	
	2. No	Moderate: Q5=2 and Q6=1
	Q6. Sample size of at least n=96 ^a	
	1. Yes	
	2. No	Weak: Q5=2 and Q6=2
Global rating for each paper:		
Strong: No weak ratings		
Moderate: one weak rating		
Weak: two or more weak ratings		

Table 2: Methodological quality of included studies

Reference	SELECTION BIAS			DATA COLLECTION METHODS			SAMPLE SIZE			GLOBAL RATING
	Representative sample	Response rate	Rating	Valid tool	Reliable tool	Rating	Sample adequate (sample size)	Sample size justified	Rating	
Ahmad, Orrell, Iliffe, and Gracie (2010)	Not likely	<60%	Weak	Can't tell	Can't tell	Weak	Yes (n=1011)	No	Moderate	WEAK
Baloch et al. (2010)	Somewhat likely	Can't tell	Moderate	Yes	Can't tell	Moderate	Yes (n=134)	No	Moderate	STRONG
Beer et al. (2009)	Somewhat likely	<60%	Weak	Can't tell	Can't tell	Weak	Yes (n=202)	No	Moderate	WEAK
Brazil et al. (2015)	Very likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=133)	No	Moderate	MODERATE
Cahill et al. (2008)	Very likely	60-79%	Moderate	Yes	Can't tell	Moderate	Yes (n=300)	No	Moderate	STRONG
Cahill et al. (2006)	Very likely	60-79%	Moderate	Yes	Can't tell	Moderate	Yes (n=300)	No	Moderate	STRONG
Cantegreil-Kallen et al. (2006)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=631)	No	Moderate	MODERATE
Fortinsky et al. (2010)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=422)	Yes	Strong	MODERATE
Fox et al. (2014)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=113)	No	Moderate	MODERATE

Reference	SELECTION BIAS			DATA COLLECTION METHODS			SAMPLE SIZE			GLOBAL RATING
	Representative sample	Response rate	Rating	Valid tool	Reliable tool	Rating	Sample adequate (sample size)	Sample size justified	Rating	
Gaboreau et al. (2014)	Somewhat likely	<60%	Weak	Can't tell	Can't tell	Weak	Yes (n=493)	No	Moderate	WEAK
Harris et al. (2009)	Somewhat likely	60-79%	Moderate	Can't tell	Can't tell	Weak	Yes (n=164)	No	Moderate	MODERATE
Hillmer et al. (2006)	Very likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=334)	Yes	Strong	MODERATE
Kaduszkiewicz et al. (2008a)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=211)	No	Moderate	MODERATE
Kaduszkiewicz et al. (2008b)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=211)	No	Moderate	MODERATE
Millard, Kennedy, and Baune (2011)	Can't tell	Can't tell	Weak	Can't tell	Can't tell	Weak	Yes (n=127)	No	Moderate	WEAK
Moorhouse et al. (2011)	Somewhat likely	<60%	Weak	Yes	Can't tell	Moderate	Yes (n=134)	No	Moderate	MODERATE
Russ et al. (2013)	Somewhat likely	80-100%	Moderate	Can't tell	Can't tell	Weak	Yes (n=267)	No	Moderate	MODERATE
Somme et al. (2013)	Very likely	60-79%	Moderate	Yes	Can't tell	Moderate	Yes (n=1058)	No	Moderate	STRONG
Stewart et al. (2014)	Very likely	60-79%	Moderate	Yes	Can't tell	Moderate	Yes (n=851)	Yes	Strong	STRONG

Reference	SELECTION BIAS			DATA COLLECTION METHODS			SAMPLE SIZE			GLOBAL RATING
	Representative sample	Response rate	Rating	Valid tool	Reliable tool	Rating	Sample adequate (sample size)	Sample size justified	Rating	
Thyrian and Hoffmann (2012)	Somewhat likely	<60%	Weak	Yes	Yes	Strong	Yes (n=335)	No	Moderate	MODERATE

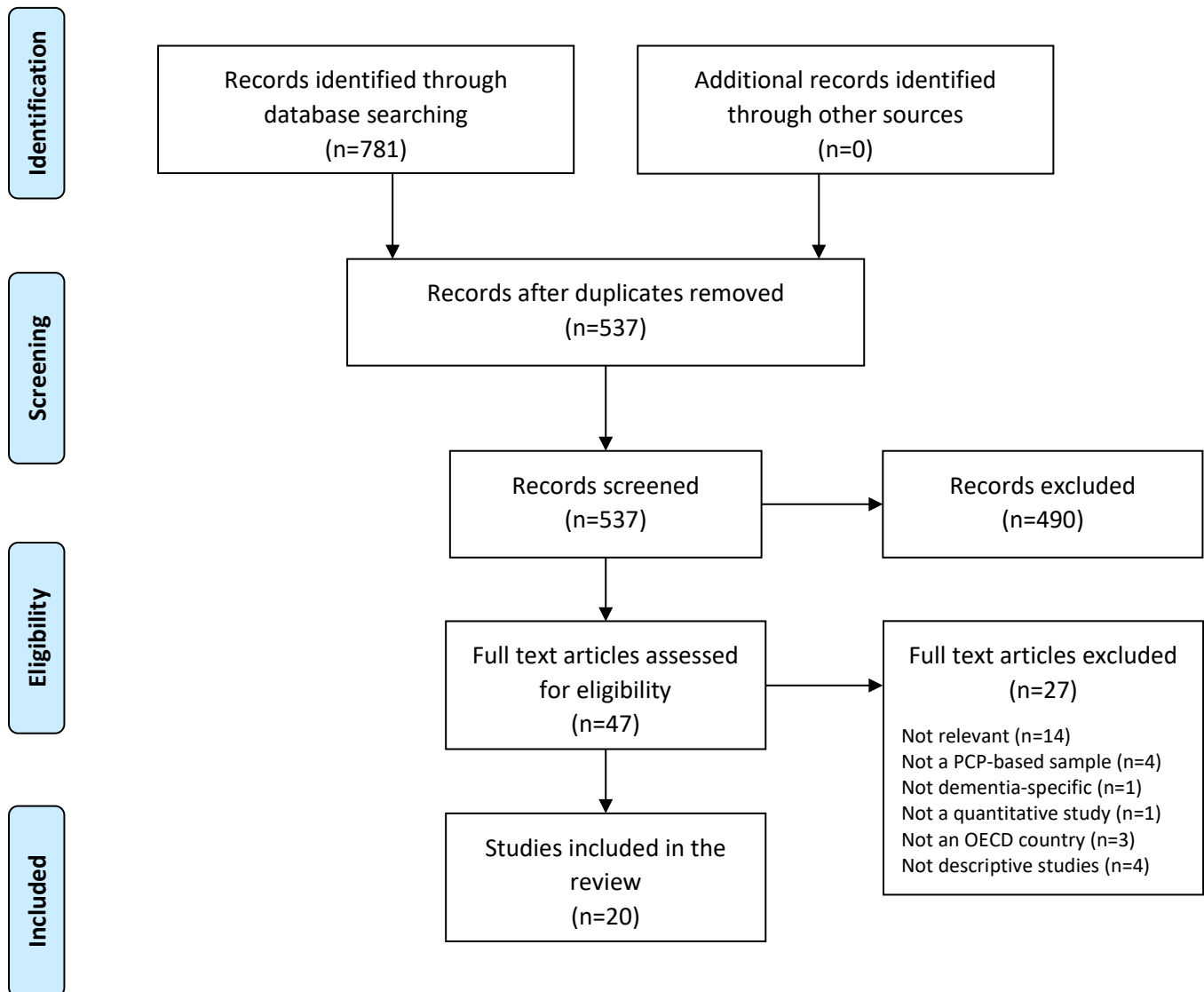


Figure 1. PRISMA diagram of article screening process.

Supplementary file 1: Search terms**Database: MEDLINE 1946 to Present with Daily Update****Search Strategy:**

-
- 1 dementia/ or alzheimer disease/ (109206)
 - 2 (dementia* or alzheimer*).ti,ab. (141201)
 - 3 1 or 2 (158168)
 - 4 ((general or family) adj1 (practice* or practitioner*)).tw. (71085)
 - 5 General Practitioners/ (4794)
 - 6 Physicians, Family/ (15445)
 - 7 ("primary care physician*" or "primary care physician").ti,ab. (24723)
 - 8 exp General Practice/ (69006)
 - 9 Primary Health Care/ (60825)
 - 10 ("primary care" or "primary medical care" or "primary health care" or "primary healthcare" or "primary health service").ti,ab. (89518)
 - 11 4 or 5 or 6 or 7 or 8 or 9 or 10 (206327)
 - 12 "Attitude of Health Personnel"/ (100699)
 - 13 (barrier* or enabler* or obstacle* or challenge*).tw. (562695)
 - 14 Practice Patterns, Physicians'/ (47223)
 - 15 Health Knowledge, Attitudes, Practice/ (84719)
 - 16 Clinical Competence/ (73870)
 - 17 12 or 13 or 14 or 15 or 16 (812612)
 - 18 3 and 11 and 17 (491)
 - 19 limit 18 to english language (437) [+ humans] (436)
 - 20 limit 19 to (comment or editorial or letter or news) (24)
 - 21 19 not 20 (413) = (412)

Database: MEDLINE In-Process & Other Non-Indexed Citations**Search Strategy:**

-
- 1 dementia/ or alzheimer disease/ (0)
 - 2 (dementia* or alzheimer*).ti,ab. (14810)
 - 3 1 or 2 (14810)
 - 4 ((general or family) adj1 (practice* or practitioner*)).tw. (5193)
 - 5 General Practitioners/ (0)
 - 6 Physicians, Family/ (0)
 - 7 ("primary care physician*" or "primary care physician").ti,ab. (2782)
 - 8 exp General Practice/ (0)
 - 9 Primary Health Care/ (0)
 - 10 ("primary care" or "primary medical care" or "primary health care" or "primary healthcare" or "primary health service").ti,ab. (10232)
 - 11 4 or 5 or 6 or 7 or 8 or 9 or 10 (15299)
 - 12 "Attitude of Health Personnel"/ (0)
 - 13 (barrier* or enabler* or obstacle* or challenge*).tw. (90065)
 - 14 Practice Patterns, Physicians'/ (0)
 - 15 Health Knowledge, Attitudes, Practice/ (0)
 - 16 Clinical Competence/ (0)
 - 17 12 or 13 or 14 or 15 or 16 (90065)
 - 18 3 and 11 and 17 (30)
 - 19 limit 18 to english language (26)
 - 20 limit 19 to (comment or editorial or letter or news) (0)
 - 21 19 not 20 (26)

Database: Embase <1974 to 2016 Week 25>**Search Strategy:**

-
- 1 exp dementia/ (270933)
 - 2 (dementia* or alzheimer*).ti,ab. (211999)
 - 3 1 or 2 (304591)
 - 4 ((general or family) adj1 (practice* or practitioner*)).tw. (96175)
 - 5 general practitioner/ (74251)
 - 6 ("primary care physician*" or "primary care physician").ti,ab. (35047)
 - 7 general practice/ (75057)
 - 8 ("primary care" or "primary medical care" or "primary health care" or "primary healthcare" or "primary health service*).ti,ab. (126872)
 - 9 exp primary health care/ (126514)
 - 10 4 or 5 or 6 or 7 or 8 or 9 (309397)
 - 11 health personnel attitude/ or physician attitude/ (112152)
 - 12 (barrier* or enabler* or obstacle* or challenge*).tw. (793043)
 - 13 clinical practice/ (204506)
 - 14 attitude to health/ (89877)
 - 15 clinical competence/ (48136)
 - 16 11 or 12 or 13 or 14 or 15 (1183045)
 - 17 3 and 10 and 16 (935)
 - 18 limit 17 to english language (856) +humans^{nn added} = 811
 - 19 limit 18 to (book or book series or chapter or conference abstract or conference paper or conference proceeding or "conference review" or editorial or letter or note) (281)
 - 20 18 not 19 (575)

Database: PsycINFO <1806 to June Week 3 2016>**Search Strategy:**

-
- 1 exp Dementia/ (60895)
 - 2 Alzheimer's disease/ (37028)
 - 3 (dementia* or alzheimer*).ti,ab. (77355)
 - 4 1 or 2 or 3 (80019)
 - 5 ((general or family) adj1 (practice* or practitioner*)).tw. (14278)
 - 6 general practitioners/ or family medicine/ or primary care physicians/ (7575)
 - 7 ("primary care physician*" or "primary care physician").ti,ab. (5840)
 - 8 primary health care/ (14608)
 - 9 ("primary care" or "primary medical care" or "primary health care" or "primary healthcare" or "primary health service*).ti,ab. (26452)
 - 10 5 or 6 or 7 or 8 or 9 (41984)
 - 11 health personnel attitudes/ (15991)
 - 12 (barrier* or enabler* or obstacle* or challenge*).tw. (212927)
 - 13 clinical practice/ (15276)
 - 14 treatment barriers/ (3194)
 - 15 health knowledge/ or health attitudes/ (14459)
 - 16 11 or 12 or 13 or 14 or 15 (251974)
 - 17 4 and 10 and 16 (209)
 - 18 limit 17 to english language (200) +humans^{nn added} =198
 - 19 limit 18 to (chapter or "column/opinion" or "comment/reply" or dissertation or editorial or letter) (36)
 - 20 18 not 19 (164)
 - 21 limit 20 to "0200 book" (6)

22 20 not 21 (158)

Cochrane Library search strategy

ID	Search Hits
#1	MeSH descriptor: [Dementia] explode all trees 4284
#2	MeSH descriptor: [Alzheimer Disease] explode all trees 2412
#3	(dementia* or alzheimer*):ti,ab,kw (Word variations have been searched) 9913
#4	#1 or #2 or #3 10118
#5	"general practice*" or "general practitioner*":ti,ab,kw (Word variations have been searched) 7097
#6	"family practice*" or "family practitioner*":ti,ab,kw (Word variations have been searched) 2595
#7	MeSH descriptor: [General Practitioners] explode all trees 145
#8	MeSH descriptor: [Physicians, Family] explode all trees 475
#9	"primary care physician*" or "primary care physician*":ti,ab,kw (Word variations have been searched) 1735
#10	MeSH descriptor: [General Practice] explode all trees 2471
#11	MeSH descriptor: [Primary Health Care] explode all trees 5831
#12	"primary care" or "primary medical care" or "primary health care" or "primary health service":ti,ab,kw (Word variations have been searched) 11152
#13	#5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 19005
#14	MeSH descriptor: [Attitude of Health Personnel] explode all trees 1958
#15	(barrier* or enabler* or obstacle* or challenge*):ti,ab,kw (Word variations have been searched) 20620
#16	MeSH descriptor: [Practice Patterns, Physicians'] explode all trees 1217
#17	MeSH descriptor: [Health Knowledge, Attitudes, Practice] explode all trees 4521
#18	MeSH descriptor: [Clinical Competence] explode all trees 2371
#19	#14 or #15 or #16 or #17 or #18 29122
#20	#4 and #13 and #19 32

CINAHL Search strategy

1	(TI Dementia* or AB Dementia*) or (TI Alzheimer* or AB Alzheimer*)	43746
2	IT "General practice*" or AB "general practice*") or (TI "General practitioner*" or AB "General practitioner*")	18797
3	(TI "Family practice*" or AB "Family practice*") or (TI "Family practitioner*" or AB TI "Family practitioner*")	2049
4	MH Physicians, Family	13133
5	(TI "Primary care physician*" or AB "Primary care physician*") or (TI "Primary care physician*" or AB "Primary care physician*")	5187
6	MH "Primary Health Care"	43841
7	(TI "Primary care" or AB "Primary care") or (TI "Primary Medical care" or AB "Primary Medical care") or (TI "Primary health care" or AB "Primary health care") or (TI "Primary healthcare" or AB "Primary healthcare") or (TI "Primary health service*" or AB "Primary health service*")	48507
8	2 or 3 or 4 or 5 or 6 or 7	90489
9	(TI Barrier* or AB Barrier*) or (TI enabler* or AB enabler*) or (TI obstacle* or AB obstacle*) or (TI challenge* or AB challenge*)	139657
10	MH "Practice Patterns"	11520
11	MH "Clinical Competence"	28346
12	MH "Attitude of Health Personnel"	29427
13	9 or 10 or 11 or 12	200743

16	1 and 8 and 13	181
17	1 and 8 and 13 Narrow by Language-english	173

Supplementary file 2. PCPs' perceptions of barriers within studies rated 'moderate' or 'strong' on methodological criteria

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
Barriers to dementia diagnosis			
<i>Patient-related</i>			
Comprehension	38%: concerns about the patient's ability to comprehend the diagnosis (Cahill et al., 2006)	Ireland	2006
Impact on patient	28%: concerns about impact of the diagnosis on the patient (Cahill et al., 2006)	Ireland	2006
Misunderstanding/ denial	61%: patients do not wish to have cognitive impairment acknowledged (Kaduszkiewicz et al., 2008a) NR ^a : misunderstanding, including the belief that cognitive decline is a normal part of aging (Cahill et al., 2008)	Germany, Ireland	2008
Preference for no diagnosis	28%: Families prefer not to be told about their relative's dementia early (Fox et al., 2014)	UK	2014
Stigma/ embarrassment	75%: patients feel ashamed of cognitive decline (Kaduszkiewicz et al., 2008a) NR ^a : Stigma, denial, embarrassment (Cahill et al., 2008)	Germany, Ireland	2008
<i>Provider-related</i>			
Lack of training/ knowledge	10%: Low competence in diagnosis of dementia (Kaduszkiewicz et al., 2008b) 10%: PCPs not clear which service to refer patients to for diagnosis/ care (Russ et al., 2013) 19%: Insufficient training in identification of dementia (Fox et al., 2014) 31%: Difficulty differentiating dementia from normal aging (Cahill et al., 2006) 40%: Insufficient training in communicating a diagnosis (Somme et al., 2013) 50%: Need for further training on how to communicate with people with dementia and carers (Kaduszkiewicz et al., 2008b)	France, Germany, Ireland, UK, USA	2006, 2008, 2010, 2013, 2014

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
	63%: Insufficient training in evaluation and management of dementia (Baloch et al., 2010) NR ^a : Lack of PCP education (Cahill et al., 2008)		
Lack of confidence/comfort in making a diagnosis	23%: Uncomfortable in making a diagnosis (Baloch et al., 2010) 30%: Lack of confidence (Cahill et al., 2006) 66%: Lack of confidence (Thyrian & Hoffmann, 2012) NR ^a : Lack of confidence (Cahill et al., 2008)	Germany, Ireland, USA	2006, 2008, 2010, 2012
Lack of benefit of diagnosis	15%: No benefit of early diagnosis; 19%: No benefit of diagnosis as there is no cure; 30%: Providing a dementia diagnosis can be more harmful than helpful (Fox et al., 2014) 30%: People with dementia should not be informed early (Kaduszkiewicz et al., 2008a & 2008b) NR ^a : No value in early diagnosis/therapeutic nihilism (Cahill et al., 2008)	Germany, Ireland, UK	2008, 2014
<i>System-related</i>			
Lack of time	41%: Lack of time during clinic visits to provide optimal dementia care (Fortinsky et al., 2010) 51%: Length of time needed to administer screening tools (Stewart et al., 2014) 78%: Inadequate clinician time (Stewart et al., 2014) 86%: PCP needs more time for people with dementia/carers (Thyrian & Hoffmann, 2012) NR ^a : Lack of time for screening during short consultations (Cahill et al., 2008)	Germany, Ireland, USA	2008, 2010, 2012, 2014
Lack of support/specialist services/resources	20%: Lack of specialists/ resources in the community (Stewart et al., 2014) 23%: Lack of support staff for the provision of optimal dementia care (Fortinsky et al., 2010)	Ireland, UK, USA	2008, 2010, 2014

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
	29%: Lack of support for those diagnosed (Fox et al., 2014) 46%: Lack of local diagnostic services (Fox et al., 2014) 57 - 59%: Lack of immediate access to Old Age Psychiatry and Geriatric services respectively (Cahill et al., 2008)		
Poor care coordination	4%: PCPs not clear about their role in shared care for dementia (Russ et al., 2013) 70%: Need to improve co-operation with other clinicians (Thyrian & Hoffmann, 2012)	Germany, UK	2012, 2013
Need for guidelines	56%: Need for guidelines for diagnosis and treatment of dementia (Kaduszkiewicz et al., 2008b) 91%: Guidelines for screening and diagnosis would increase detection of dementia (Baloch et al., 2010)	Germany, USA	2008, 2010
Need for better tools	40% Need for better screening tools (Stewart et al., 2014) 48%: Need for better diagnostic tools (Stewart et al., 2014)	USA	2014
Lack of financial support for people with dementia/carers	35%: Expense for referral to specialists (Stewart et al., 2014)	USA	2014
Inadequate reimbursement	32%: Lack of reimbursement for PCPs to provide optimal dementia care (Fortinsky et al., 2010) 82%: Mandatory health insurance budget per patient restricts adequate care (Thyrian & Hoffmann, 2012)	Germany, USA	2010, 2012
Lack of community engagement	77%: Need for improved public education about dementia (Thyrian & Hoffmann, 2012)	Germany	2012
Barriers to dementia management			
<i>Patient-related</i>			

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
Impact on patients or physician-patient relationship	43%: Concern about the impact on physician-patient relationship of assessing fitness to drive (Moorhouse et al., 2011) 56%: Perception that informing families about the prognosis for severe dementia will unnecessarily increase anxiety for people with dementia and family (Brazil et al., 2015)	Canada, UK	2011, 2015
Non-compliance with treatment	19% - 54%: non-compliance with nursing care and psychosocial support respectively (Cantegreil-Kallen et al., 2006) 72%: lack of compliance with medications (Hillmer et al., 2006)	Canada, France	2006
Lack of support from carers	27%: Lack of support for assessing fitness to drive (Moorhouse et al., 2011) 66%: Lack of a reliable informant for planning psychosocial support (Cantegreil-Kallen et al., 2006)	Canada, France	2006, 2011
<i>Provider-related</i>			
Negative perceptions /perceived lack of benefits associated with dementia care	11%: No perceived benefit of informing families about the prognosis for severe dementia; 44%: Lack of agreement that ACPs should be revisited with person with dementia and family frequently; 46%: lack of agreement that ACP should be initiated at the time of diagnosis (Brazil et al. 2015) 15%: Primary care cannot significantly improve quality of life of people with dementia (Harris et al., 2009) 15%: PCPs showed a negative attitude towards caring for people with dementia (Kaduszkiewicz et al., 2008b) 74%: PCPs considered behavioural disorders difficult to manage (Somme et al., 2013) 77%: Older people with dementia are difficult to manage in primary care (Harris et al., 2009)	France, Germany, UK, USA	2008, 2009, 2013, 2015
Lack of knowledge/training in general	5%: General lack of knowledge of dementia (Cantegreil-Kallen et al. 2006)	Canada, France, Germany, USA	2006, 2008, 2010, 2011, 2012

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
	6%: Low level of competence for managing dementia (Kaduszkiewicz et al., 2008b)		
	37%: Lack of knowledge of standards and guidelines for assessing fitness to drive (Moorhouse et al., 2011)		
	63%: Insufficient training in evaluation and management of dementia (Baloch et al., 2010)		
	66%: Not feel competent to provide dementia care (Thyrian & Hoffman 2012)		
Lack of training in communication with people with dementia/carers	20% to 33%: Insufficient training in communication with families and people with dementia respectively (Somme et al., 2013)	France, Germany	2008, 2013
	50%: Need for further training on how to communicate with people with dementia and carers (Kaduszkiewicz et al., 2008b)		
Lack of knowledge/training about treatment options	10%: Lack of knowledge about cholinesterase inhibitors (Hillmer et al., 2006)	Canada, USA, France	2006, 2010, 2013
	14%: Unfamiliar with advances in medication (Fortinsky et al., 2010)		
	23%: Unfamiliar with non-pharmacological management (Fortinsky et al., 2010)		
	45%: Lack of continuing medical education on cholinesterase inhibitors in the last year (Hillmer et al. 2006)		
	48%: Insufficient training in non-drug treatments for dementia (Somme et al., 2013)		
Lack of knowledge/training about end of life care	80%: PCPs need improved knowledge about involving families in caring for people with dementia at the end of life (Brazil et al., 2015)	UK	2015
Lack of confidence/comfort in managing dementia	14%: Not confident advising on management of dementia symptoms (Fox et al., 2014)	Canada, France, UK	2011, 2013, 2014
	23%: Not comfortable in their role managing dementia (Somme et al., 2013)		
	40%: Lack of comfort in decision making regarding fitness to drive (Moorhouse et al., 2011)		

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
Lack of knowledge about support services	<p>10%: PCPs not clear which service to refer people with dementia to (Russ et al., 2013)</p> <p>37%: Unfamiliar with available community resources (Fortinsky et al., 2010)</p> <p>37%: Not confident to advise on available support services (Fox et al., 2014)</p> <p>45%: Not confident providing information about social assistance (Somme et al., 2013)</p> <p>56%: PCPs insufficiently informed about community care services (Cantegreil-Kallen et al., 2006)</p>	France, UK, USA	2006, 2010, 2013, 2014
<i>System-related</i>			
Lack of time	<p>41%: Lack of time during clinic visits to provide optimal dementia care (Fortinsky et al., 2010)</p> <p>78%: Inadequate clinician time (Stewart et al., 2014)</p> <p>86%: PCP needs more time for people with dementia/carers (Thyrian & Hoffmann, 2012)</p>	Germany, USA	2010, 2012, 2014
Lack of support/specialist services/resources	<p>11% - 40%: Lack of available geriatric care assistance for people with dementia and lack of educational support for carers respectively (Cantegreil-Kallen et al., 2006)</p> <p>20%: Lack of specialists/ resources in the community (Stewart et al., 2014)</p> <p>23%: Lack of support staff for the provision of optimal dementia care (Fortinsky et al., 2010)</p> <p>30%: Lack of expertise and referral resources with the organisation (Harris et al., 2009)</p> <p>41%: Lack of resources to offer people with dementia regarding fitness to drive (Moorhouse et al., 2011)</p> <p>47%: Inpatient care is not easily accessible (Russ et al., 2013)</p>	Canada, France, Germany, UK, USA	2006, 2009, 2010, 2011, 2012, 2013, 2014

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
	72%: Need for better information for carers (Thyrian & Hoffmann, 2012)		
Poor care coordination	4%: PCPs not clear about their role in shared care for dementia (Russ et al., 2013) 34% - 58%: Difficulty collaborating with health care professionals and social workers respectively (Cantegreil-Kallen et al., 2006) 44%: Struggle with care coordination and information sharing within the healthcare organization (Harris et al., 2009) 48%: Found coordination of care difficult (Somme et al., 2013) 70%: Need to improve co-operation with other clinicians (Thyrian & Hoffmann, 2012)	France, Germany, UK, USA	2006, 2009, 2012, 2013
Inadequate reimbursement	32%: Lack of reimbursement for PCPs to provide optimal dementia care (Fortinsky et al., 2010) 82%: Mandatory health insurance budget per patient restricts adequate care (Thyrian & Hoffmann, 2012)	Germany, USA	2010, 2012
Need for guidelines	56%: Need for guidelines for diagnosis and treatment of dementia (Kaduszkiewicz et al., 2008b)	Germany	2008
Lack of financial support for people with dementia/carers	16%: Financial problems for families for using psychosocial interventions (Cantegreil-Kallen et al., 2006) 35%: Expense for referral to specialists (Stewart et al., 2014) 45%: Need to improve financial support for carers (Thyrian & Hoffmann, 2012)	France, Germany, USA	2006, 2012, 2014
Lack of treatment options	48%: Limited treatment options (Stewart et al., 2014)	USA	2014
Lack of carer involvement	66%: Need for carers to be more integrated into treatment and care (Thyrian & Hoffman, 2012) 82%: People with dementia/ carers need improved social participation outside the health care system (Thyrian & Hoffmann, 2012)	Germany	2012

Type of barrier	Proportion of respondents reporting barrier	Countries in which barrier reported	Years barrier reported
Lack of community engagement	77%: Need for improved public education about dementia (Thyrian & Hoffmann, 2012)	Germany	2012
Liability	78%: Concern about personal/ corporate liability for assessing fitness to drive (Moorhouse et al., 2011)	Canada	2011
General barriers to diagnosis and management			
<i>Patient-related</i>			
N/A			
<i>Provider related</i>			
Lack of knowledge/ insufficient training	63%: Insufficient training in evaluation and management of dementia (Baloch et al., 2010)	USA	2010
<i>System-related</i>			
Lack of time	78%: Inadequate clinician time (Stewart et al., 2014) 86%: PCP needs more time for people with dementia/carers (Thyrian & Hoffmann, 2012)	Germany, USA	2012, 2014
Lack of support/specialist services/resources	20%: Lack of specialists/resources in the community (Stewart et al., 2014)	USA	2014
Poor care coordination	70%: Need to improve co-operation with other clinicians (Thyrian & Hoffmann, 2012)	Germany	2012
Need for guidelines	56%: Need for guidelines for diagnosis and treatment of dementia (Kaduszkiewicz et al., 2008b)	Germany	2008
Lack of financial support for people with dementia/carers	35%: Expense for referral to specialists (Stewart et al., 2014)	USA	2014
Inadequate reimbursement	82%: Mandatory health insurance budget per patient restricts adequate care (Thyrian & Hoffmann, 2012)	Germany	2012
Lack of community engagement	77%: Need for improved public education about dementia (Thyrian & Hoffmann, 2012)	Germany	2012

^aNR: Proportion of respondents not reported