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Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners

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Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners

Abstract

The aim of this study is to systematically review practitioners' practices and attitudes in regards to communicating a diagnosis of dementia. A systematic search was conducted of Scopus, Web of Science and PubMed for English language original empirical papers. A sequential explanatory mixed studies analysis approach was used. Twenty-five quantitative descriptive, two intervention, six mixed methods descriptive and 21 qualitative studies were included. Pooled analysis showed that 34% of GPs and 48% of specialists usually/routinely tell the person with dementia their diagnosis, and 89% of GPs and 97% of specialists usually/routinely tell the family the diagnosis. Euphemistic terms such as 'memory problems' are more often used to describe dementia than medical terms. Practitioners' decision to diagnose and communicate the diagnosis of dementia are influenced by (a) their own beliefs regarding dementia and treatment efficacy and their confidence in diagnosis and communication; (b) patient circumstances including level of awareness, level of severity and family support; (c) the health and social care system including access to specialist and diagnostic services, reimbursement for diagnosis/management and availability of services and (d) cultural norms in relation to dementia including stigma, labels, and common clinical practice. The diagnosis and communication of diagnosis of dementia are intertwined processes and should be concurrently addressed in interventions. Multicomponent approaches to address these practices could include guideline development, practitioner education, anti-stigma public health campaigns, offering post-diagnosis treatments and support and sufficient reimbursement for practitioners for time spent managing dementia.

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Communicating a diagnosis of dementia

Communicating a diagnosis of dementia: a systematic mixed studies review of attitudes and practices of health practitioners

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Abstract

The aim of this study is to systematically review practitioners' practices and attitudes in regards to communicating a diagnosis of dementia. A systematic search was conducted of Scopus, Web of Science and PubMed for English language original empirical papers. A sequential explanatory mixed studies analysis approach was used. Twenty-five quantitative descriptive, two intervention, six mixed methods descriptive and 21 qualitative studies were included. Pooled analysis showed that 34% of GPs and 48% of specialists usually/routinely tell the person with dementia their diagnosis, and 89% of GPs and 97% specialists usually/routinely tell the family the diagnosis. Euphemistic terms such as 'memory problems' are more often used to describe dementia than medical terms. Practitioners' decision to diagnose and communicate the diagnosis of dementia are influenced by a) their own beliefs regarding dementia and treatment efficacy, and their confidence in diagnosis and communication; b) patient circumstances including level of awareness, level of severity and family support; c) the health and social care system including access to specialist and diagnostic services, reimbursement for diagnosis/management and availability of services; and d) cultural norms in relation to dementia including stigma, labels, and common clinical practice. The diagnosis and communication of diagnosis of dementia are intertwined processes and should be concurrently addressed in interventions. Multicomponent approaches to address these practices could include guideline development, practitioner education, anti-stigma public health campaigns, offering post-diagnosis treatments and support, and sufficient reimbursement for practitioners for time spent managing dementia.

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Keywords: disclosure, truth-telling, ethics, Alzheimer's Disease, dementia, general practitioners

Introduction

Almost two thirds (63.7%, 95% CI 54.8% to 71.8%) of dementia cases in the community are not diagnosed (Lang et al., 2017). The physician or team that makes the diagnosis has the responsibility to communicate it, so we assume that the person making the diagnosis of dementia also communicates it. Primary care practitioners or general practitioners (GPs) play a central role in the diagnosis of dementia (Geldmacher and Kerwin, 2013), hence most people with dementia are told their diagnosis by a primary care practitioner or general practitioner. Recommendations suggest that when conveying a dementia diagnosis, practitioners use the term dementia (or sometimes more specifically Alzheimer's disease or another cause of dementia) except when inappropriate because of cultural or other reasons, and actively counter nihilism and despair by focusing on the functional capabilities that remain and framing the challenge as achieving the best life possible (Grossberg et al., 2010). Guidelines also recommend that when giving the diagnosis the practitioner should address issues including remaining diagnostic uncertainty, treatment options, future plans, financial planning, assigning power of attorney, wills and "living wills", driving privileges and the need for eventual driving cessation, available support services, and that information should be provided in accessible verbal and written formats (Fisk et al., 2007, Clinical Adaptation Committee, 2016). There appears to be a disconnect between guidelines for communicating a diagnosis of dementia, and medical practice in the community (Carpenter and Dave, 2004).

Communicating the diagnosis can be thought of as truth-telling or honest communication about the condition and prognosis, as well as a willingness to explore

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and meet information needs (Hancock et al., 2007). We have purposely used the terms 'communicating' or 'telling' the diagnosis rather than the commonly used term 'disclosing' because disclosing implies sharing a secret, and we do not wish to imply that a diagnosis of dementia is a secret to be hidden or revealed.

General practitioners find communicating the diagnosis of dementia difficult (Phillips et al., 2012, Karnieli-Miller et al., 2007b, Moore and Cahill, 2013) and that managing dementia is more frustrating than rewarding (Pathak and Montgomery, 2015b, Liu et al., 2013). There is variability in how the diagnosis is communicated terms of who gives the diagnosis, who is told, and what terms are used (Kissel and Carpenter, 2007, Moore and Cahill, 2013).

In the field of cancer, poor communication has detrimental impacts on patient decisions about treatment, and unintended psychosocial consequences including heightened anxiety and depression, poor psychological adjustment, hopelessness and reduced quality of life (Thorne et al., 2005). The dementia literature fails to disentangle the impact of the symptoms of dementia from the way the diagnosis is communicated. However people with dementia have written about how the post-diagnosis information had negative impacts on their view of themselves and the future (Swaffer, 2015). Our systematic review of experiences of people with early dementia found that diagnosis is a key point of disempowerment, with insufficient information provided about dementia, limited treatments and supports and 'hope' offered (Low et al., 2017).

Practitioner training in medical ethics stress the principles of autonomy, justice, beneficence and non-maleficence. When communicating a diagnosis of dementia,

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practitioners must balance these principles (Whitehouse, 2000). Autonomy is supported when the person with dementia is told the diagnosis (as long as they want to know), by allowing them to plan care, seek other opinions, choose treatments and put their affairs in order. Deception about the diagnosis fails to respect patient's autonomy as a self-determining, self-governing being (Tuckett, 2004). A systematic review found that the majority of people without cognitive impairment and memory clinic attendees of those with dementia wanted to be told if they had dementia (90.7% (95%CI: 83.8%–97.5%) and 84.8% (95%CI: 75.6%–94.0%) respectively).(van den Dungen et al., 2014). While memory clinic attendees may not be representative of older people, this suggests that many would want to know if they had dementia.

Common beneficent reasons for telling the diagnosis are to facilitate planning, because knowing would have psychological benefits for the person and/or their carer, to maximise treatment, to obtain a second opinion, because the person with dementia wants to know, so they can plan travel or a vacation.(Bamford et al., 2004) However practitioners may view telling the diagnosis as having negative (maleficent) repercussions, or that they are being beneficent by not telling or delaying. This relates to beliefs that that nothing can be done for dementia (Moore and Cahill, 2013), that giving the diagnosis will damage the patient doctor relationship (Mason et al., 2016, Phillips et al., 2012), and that knowing the diagnosis will have negative psychological impacts on the patient (Moore and Cahill, 2013, Pathak and Montgomery, 2015b). The aim of this study is to systematically review research on practitioners' practices and attitudes in regards to communicating a diagnosis of dementia. Specifically we are interested in 1) the proportion of practitioners who usually communicate the dementia

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diagnosis; 2) how the diagnosis is communicated; and 3) factors that impact on whether the diagnosis is communicated.

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Methods

A systematic search was undertaken (see figure 1) in September 2016 of the databases Scopus, Web of Science and PubMed, no restrictions were set on publication date.

Reference lists of included articles and relevant reviews were hand-searched.

Search terms were

(1) dementia OR alzheimer (all fields);*

(2) "general practitioner" or "doctor" or "primary care physician" or "neurologist" or "geriatrician" or "psychogeriatrician" or "memory clinic" or "memory disorders clinic" or "memory service";

(3) diagnosis;

(4) 1 AND 2 AND 3.

Inclusion criteria:

(1) Original, empirical data

(2) Quantitative, qualitative or mixed methods papers study that addresses the communication of a diagnosis of dementia and related attitudes and beliefs by health practitioners in primary care or specialist settings

(3) Paper in English language

Information extracted from included papers

- Bibliographic details
- Aim

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- Setting and study population; sampling criteria and recruitment method
- Participant numbers, demographics, and response rates
- Questions asked of participants or outcome measures/instruments used relating to communicating diagnosis
- Data analysis methods
- Key results relating to communicating diagnosis

The quality of each paper was rated using the Mixed Methods Appraisal Tool (Pace et al., 2012). The mixed methods appraisal tool has been designed to be suitable for use in reviews that include qualitative, quantitative and mixed methods studies. There are separate criteria for rating each methodological design (i.e. qualitative (4 criteria), quantitative randomized controlled trials (4 criteria), quantitative non-randomised (4 criteria), quantitative descriptive (4 criteria), and mixed methods (3 criteria)). Mixed methods studies are rated on qualitative, quantitative and mixed methods criteria. The number of criteria met by each study was divided by the number of applicable criteria (e.g. 3/4 or 7/11) and converted into a percentage.

We use the generic term practitioners or health practitioners to describe a mixture of professions (i.e. primary care physicians, specialists, nurses and allied health), primary care physicians to describe PCPs or general practitioners, and specialists to describe geriatricians, neurologists, psychiatrists, psychogeriatricians or neuropsychiatrists.

Analysis

A sequential explanatory mixed studies approach was undertaken (Pluye and Hong, 2014) (see figure 1).

- 1) Studies were classified as quantitative or qualitative, or mixed methods.
- 2) Quantitative papers and quantitative components of mixed methods papers were examined for:
 - a) The proportion of practitioners who usually/routinely/always communicated a diagnosis of dementia, or the frequency by which the dementia diagnosis was communicated by practitioners. These data were combined, as both ultimately reflect the proportion of patients/families of practitioners in the study who would be told their dementia diagnosis.
 - b) Frequency of different terms used
 - c) Factors impacting on whether the diagnosis is communicated

A second reviewer checked extracted data from these studies. Quantitative results were summarized in tables and text. Comprehensive Meta Analysis software (<https://www.meta-analysis.com/>) was used to pool data on the proportion of practitioners who usually/routinely/always communicated the diagnosis of dementia to patients and families (Barendregt et al., 2013). Random effects models were used, as we did not assume that the same effect size underpinned studies from different countries and professional backgrounds.

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Other quantitative data were not pooled as there were heterogeneity in how questions were asked.

- 3) Informed by the quantitative findings in 2), and with a view of understanding factors impacting on practitioner behaviour, thematic analysis was undertaken of qualitative papers and qualitative components of mixed methods data (Thomas and Harden, 2008). Saturation was reached as later papers no longer yielded new themes. A second rater independently coded 10% of randomly selected papers and themes and interpretations were discussed and consensus reached between the two raters.
- 4) Quantitative results were re-examined, presented and interpreted based on the qualitative themes.

Results

The search identified 7453 unique articles, of which 50 met inclusion criteria; an additional seven articles were identified through hand-searching. In total 57 articles (53 unique studies) were included in this review (see figure 1).

Quantitative data

Of 32 studies which provided quantitative data, 25 were descriptive only studies, two intervention studies (one of which was mixed methods) and there were six additional mixed methods descriptive studies (see table 2). All mixed methods studies prioritized quantitative data in either nested or sequential designs, hence mixed methods studies

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are presented with other quantitative papers. Results for four of these mixed methods studies were presented across two journal articles. For descriptive quantitative studies Mixed Methods Appraisal Tool scores ranged between 0% and 100%, with an average of 61 ± 28 . Weaknesses in the quantitative papers tended to relate to lack of sample representativeness and <60% response rates. Mixed methods studies tended to predominately focus on quantitative results, and had Mixed Methods Appraisal Tool scores ranging between 20% and 75% with an average of $47\% \pm 16$. Weaknesses in the mixed methods papers tended to relate to more to qualitative components, and integration of quantitative and qualitative data.

A total of 13,242 practitioners were included in quantitative and mixed methods papers. Most studies attempted to recruit a representative sample of practitioners by inviting all or randomly selected eligible practitioners within a geographical area or within certain healthcare organisations to participate; a few used convenience sampling of practitioners attending dementia training (Downs et al., 2000, McIntosh et al., 1999, Vassilas and Donaldson, 1998), participating in intervention studies (Vassilas and Donaldson, 1998), or recruited from particular practices (Van Hout et al., 2006). Two studies used a combination of representative and convenience sampling (Cody et al., 2002, Kaduszkiewicz et al., 2008a), one study used a 'market research' sample but how this was sourced was not clear (Jones et al., 2010). Participation rates ranged from 15% to 100%. Most studies used self-completed written or online surveys, two used telephone interviews (Somme et al., 2013, Rubin et al., 1987).

Proportion of practitioners who communicated the diagnosis

Fourteen studies reported data on the proportion of health professionals communicating the diagnosis to the person with dementia (Figure 2). Random-effect pooled data indicates that 34.2% (95%CI 22.7% to 47.9%) of GPs usually, regularly or always told persons with dementia the diagnosis. A greater proportion of specialists in the pooled analysis (48.3%, 95% CI 37.5% to 59.1%) usually, regularly or always told the person with dementia the diagnosis.

Six studies reported data on the proportion of health professionals communicating a diagnosis of dementia to family Figure 3. Random-effect pooled data found that 88.7% (95% CI 73.3% to 95.8%) of GPs and 96.5% (93.3% to 97.2%) of specialists usually, routinely or always communicated to family the diagnosis.

There appeared to be no relationship between the year the study was conducted and the proportion of health professionals communicating a diagnosis. We could also discern no pattern between study country and likelihood of communicating the diagnosis.

The statistical associations between telling the diagnosis and demographic and other characteristics were examined in a few studies. Greater likelihood of telling the diagnosis was associated with the practitioner being male (Somme et al., 2013, Cody et al., 2002) and younger (Somme et al., 2013, Tarek et al., 2009, Downs et al., 2002), or working in a practice with two or more practitioners (Van Hout et al., 2006). Two studies reported contradictory findings on how severity of dementia related to whether the diagnosis was told. One study reported that more severe cognitive impairment was

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related to greater likelihood of the diagnosis being told as there was greater certainty that the diagnosis was correct, whereas another reported that persons with mild dementia were more likely to be told as they were more likely to understand the diagnosis (Rice and Warner, 1994, Van Hout et al., 2006).

Terms used when communicating a diagnosis

Some studies asked participants to write down or select from a list the terms they used in communicating a diagnosis of dementia. Table 3 presents the percentage of practitioners who reported using certain terms when communicating a diagnosis. Generally more practitioners appeared to use euphemistic terms rather than medical terms. One study suggested that specialists were more likely to use medical terms, and practitioners to use euphemisms (De Lepeleire et al., 2004), and another two suggested that specialists used euphemistic terms more with persons with dementia and medical terms more with their family (Tarek et al., 2009, Cantegreil-Kallen et al., 2005).

Patient circumstances and other factors relating to whether diagnosis is communicated

Some studies asked doctors to select from checklists of beliefs/factors that contributed to whether they communicated a diagnosis (see table 4). There was great variability between studies in the number of practitioners endorsing each factor. For example 2% of French GPs (De Lepeleire et al., 2004) and 96% of Belgian specialists said that it was the patient's right to know (Tarek et al., 2009). There were higher percentages of practitioners who endorsed barriers to communicating diagnosis, than those who endorsed facilitators for communicating diagnosis.

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Patient insight, and certainty of diagnosis seemed to increase the likelihood that the diagnosis was told for more than half of practitioners. Patient age and financial situation were considerations in the decision to communicate a diagnosis for less than a third of practitioners. For some patient circumstances, it was not clear whether the factor increased or decreased likelihood of telling the diagnosis.

Confidence in dementia diagnosis and treatment

Across studies higher proportions of practitioners endorsed statements that there were benefits to having and being told a diagnosis, than statements suggesting that there were limited benefits to a diagnosis (see table 5). More than half of practitioners in some studies reported not being confident in aspects of dementia diagnosis, communication or management.

Health and social care system factors

Only two studies reported items relating to health and social care system factors which may impact on whether a diagnosis of dementia is made and communicated. A study from Maine, USA found that 32% of primary care physicians reported that lack of reimbursement was a barrier to dementia management, and 41% reported that not having enough time was a barrier (Fortinsky et al., 2010). A study of English and Welsh general practitioners found that 75% reported they had ready access to services and 50% found local services adequate or satisfactory (Renshaw et al., 2001).

Intervention studies

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We identified only one intervention study with the primary purpose of improving communication of dementia diagnosis in old age mental health teams. This randomized controlled trial (n = 644) had four arms that compared pen-and-paper exercises based on behaviour change theory, evidence-based information, or patient information to no intervention. The study found no impact of any of the interventions on practitioner's intended behaviour in relation to finding out what the patient already knows or suspects, using the actual words "dementia" or "Alzheimer's disease," or exploring what the diagnosis means to the patient (Eccles et al., 2009).

Another intervention study aimed to improve dementia diagnosis, treatment and care through three days of education for health professionals including physicians and nurses. The study did not quantitatively measure communication behaviour, but qualitative feedback suggested that education improved practitioners' confidence in discussing dementia with families (Galvin et al., 2012).

Qualitative findings

The twenty-one studies that presented only qualitative data included 1494 health practitioners (see table 3). One study that used the nominal group technique (where group members identify problems, brain storm solutions, then vote on these solutions) with participants attending dementia training had 990 participants (Iliffe et al., 2003). Results on the Mixed Methods Appraisal Tool ranged between 50% and 100%, with an average of $68\% \pm 18$ on these qualitative-only studies. Weaknesses in the qualitative papers almost always related to not considering how study results relate to researchers' influence and the study context.

In addition to qualitative-only papers there were seven mixed methods papers (one which was an intervention study) included in thematic analyses.

Practitioners described diagnosis and communicating the diagnosis as intertwined processes. Having the patient agree to assessment often involved discussing possible diagnoses, as well as the patient acknowledging his or her symptoms. Cognitive testing could also help the patient and/or his or her family recognise the extent of cognitive difficulties. It was often not possible to separate out factors relating to the decision to diagnose, and the decision to communicate.

'Sending them to a practitioner in dementia ... the subtext is... we want to know if you've got dementia or not.' (GP, Phillips et al., 2012)

Whether to communicate a diagnosis of dementia

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Figure 4 depicts an overview of themes that relate to a practitioner's decision to diagnose dementia and communicate the diagnosis.

The decision to diagnose and communicate the diagnosis of dementia is decided on a case by case basis, and is influenced by the patient's circumstance (level of severity, awareness of symptoms and family support and needs), practitioner's characteristics (beliefs regarding dementia and treatment efficacy, confidence in diagnosis and communication), the health and social care system within which they function (access to specialists and diagnostic services, reimbursement for diagnosis/management, availability of dementia services) and cultural norms in relation to dementia (stigma in the community and common clinical practice).

The decision to diagnose is made on case-by-case basis

Practitioners seemed to decide on a case-by-case basis whether to diagnose and communicate about dementia for that patient at the point in time, rather than working according to best-practice guidelines or clinical rules of thumb. They balanced the perceived benefits to the patient (and sometimes their family) with the perceived disadvantages at that point of time.

"What you're presented with is not a patient with a particular score in the test, but a patient living a particular life in particular set of circumstances, with a particular range of family members and a particular range of expectations about what they would like to see in their healthcare management." (GP, Dhedhi et al., 2014)

The GPs took a contextual attitude towards the issue of diagnosing dementia. That is,

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they tended not to make general statements about how dementia is usually diagnosed or how it should be diagnosed; instead, they described the issue of diagnosis as closely related to the characteristics of patients, their overall health and social situation, and the availability of services. (Researcher, Hansen et al., 2008)

Patient circumstances

Awareness and concern about symptoms

When patients approached practitioners with concerns about symptoms and seeking assessment, practitioners were more likely to investigate and share the results of assessments. For patients with concerns, being given diagnosis may reduce anxiety associated with uncertainty, and allow them to plan for the future.

“They’re actually better knowing rather than living with this bewilderment about what is happening for them.” (Health practitioner, Iliffe et al., 2003)

By contrast, patients who were not aware of their symptoms, or were not bothered by them were less likely to be diagnosed. Practitioners spoke about the difficulty in bringing up assessment when patients and/or families were in denial. When families approached practitioners with concerns when the patients themselves were not worried, practitioners had to balance the needs of families with the wishes and rights of the patients.

Practitioners found it difficult to act against the patient’s wishes if they did not consent to assessment.

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“the hardest thing is if ... the person’s got obvious memory loss and they either, or their family, have chosen to significantly ignore it... Then trying to bring it up... it makes it harder” (GP, Phillips et al., 2012)

“I can’t go and steamroll your mother into taking a test that she will have enough insight to realize is a direct attack on her ability to keep coping.” (GP, Hansen et al., 2008)

Severity of dementia and ability to understand the diagnosis

The patient’s stage of dementia and related ability to comprehend the diagnosis impacted on whether and how the diagnosis was made and communicated. However, views differed between studies on how practitioners behaved depending on the stage of dementia. For some practitioners, there was a greater imperative to diagnose and tell people with mild dementia, as they were able to comprehend the diagnosis, knowing may help them understand their symptoms and so they can be involved in decisions about therapy and future planning. Other practitioners were more reluctant to diagnose and tell the diagnosis to people with mild dementia because this would cause undue distress without benefits as the person would be unable to access services at that stage. For patients with mild dementia, there were mixed opinions as to whether to tell their family as some thought it was the patient’s choice but others thought family should be told.

“..giving them a diagnosis helps to explain what their problems are and why they’re feeling maybe a lack of self-confidence in themselves and their abilities. “ (Specialist,

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Kissel and Carpenter, 2007)

Despite all of the GPs in this study unequivocally claiming that an early diagnosis of dementia was important, several stated that they themselves were not proactive in the area and most were reluctant to diagnose early as they felt that a diagnosis of dementia was very difficult to give and had profound implications.(Researcher, Moore and Cahill, 2013)

Most practitioners said that they would not tell people with more severe dementia their diagnosis as they would not understand, and their rights and wishes no longer come into account.

... professionals see little point in telling someone with advanced dementia their diagnosis.(Researcher, Keightley and Mitchell, 2004)

“Actually in this case it was not that difficult, because this lady’s insight ability is not high. So I knew she will not take this so bad. That is why I could explain it explicitly. Then again, I knew she didn’t absorb half of the things said” (Specialist, Karnieli-Miller et al., 2007a)

Family

Practitioners considered the impact of the diagnosis on family – their ability to understand and access information about the diagnosis, and support and services.

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Some practitioners saw their role as primarily for the patient, others for the family.

Practitioners also described the dilemma of addressing the sometimes competing needs of both the person with dementia and the family.

“I think the thing that the diagnosis is really about is helping to prepare the family and the patients with that transition from when the patient isn't always able to care for themselves and the family isn't able to— and the transition to the family not being able to do it.”(Primary care physician,Boise et al., 1999)

Practitioners also thought that getting a diagnosis helped families plan for the future, particularly when the person with dementia needed additional help.

Physicians reported that the primary advantages of receiving a diagnosis are that family members could find out what is wrong, begin planning for the future, and be referred to services.(Researcher, Connell et al., 2004)

Practitioner characteristics

Beliefs regarding dementia and treatment efficacy

Practitioners' general beliefs about dementia, beliefs regarding treatment efficacy, and confidence in diagnosing and managing dementia appeared to influence their diagnostic behaviour. Some practitioners expressed negative attitudes towards dementia such as that it's a 'bad' diagnosis or label, or that it results in loss of personhood – these

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attitudes were associated with a reluctance to diagnose dementia. Some practitioners talked about diagnoses of specific types of dementia being unnecessary. Beliefs of practitioners about the efficacy of treatment appeared to particularly influence their diagnostic practices – specifically practitioners in many studies were skeptical about the efficacy of available medications, and did not consider ability to access these medications sufficient reason to make a diagnosis.

GPs' own innate attitudes and beliefs including fears may have resulted in their reluctance to get involved in diagnosis lest, if by becoming involved, they would be forced to confront the dilemma of either on the one hand having to convey bad news or on the other having to dissemble to protect both themselves, and their patients. Since neither situation was desirable, by not being proactive these GPs could avoid confronting this dilemma. (Researcher, Moore and Cahill, 2013)

“Since we don't have any really good medications, you say, “Is this a particular kind of dementia, multi-infarct versus Alzheimer's?”... I'm not convinced we can do a whole lot for those people.” (Primary care physician, Boise et al., 1999)

Confidence in diagnosis, communication and management

Practitioners talked about difficulties in diagnosing and managing dementia. They were hesitant to tell someone they had dementia when they were not confident in the diagnosis, and feared giving an incorrect diagnosis because of the impact on the patient and family, and doctor-patient relationships. Practitioners were sometimes reluctant to

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make predictions about prognosis. Practitioners were also uncertain about the best way to communicate the diagnosis, and an observational study described practitioners' uneasy behaviour when giving the news. Some practitioners described being demoralized by the difficulty of diagnosing and managing dementia.

Physicians in our study were reluctant to label patients as having the “disease” of dementia if they were uncertain about the diagnosis. (Researcher, Pimlott et al., 2009)

... practitioners felt inadequately trained for the task of early diagnosis, and that the diagnosis was difficult to accept for professionals as well as patients—“we know the implications of the disease process” (Researcher, Iliffe et al., 2003)

The health and social care system

Access to specialists and diagnostic services

Practitioners in some studies described difficulty accessing specialists and diagnostic services such as memory clinics or neuroimaging as hindering or delaying diagnosis. This was particularly an issue in rural samples.

During the diagnostic process, many referred patients to specialists for consultation, but this was sometimes difficult because of scheduling delays or distances some patients had to travel to reach consultants. (Researcher, Teel, 2004)

Reimbursement for diagnosis and management

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Practitioners in many studies discussed how people with dementia took longer to care for, and that standard consultations did not provide enough time to adequately detect, diagnose or manage dementia. Related to this was the issue of insufficient reimbursement for the care of people with dementia – some practitioners mentioned case management rather than assessment as being particularly underfunded.

Practitioners also discussed bureaucratic barriers relating to paperwork relating to dementia care and, in some locations, in order to access anti-cholinergic medications.

When asked to describe a substantial barrier to care, physicians simply said, “Time, time, time.” (Researcher, Pimlott et al., 2009)

Dementia created heavier paperwork demands owing to frequent need for community, social service, and specialty referrals. Physicians related that caring for persons with dementia is more time intensive for several additional reasons. Because people with dementia have impaired recent (i.e., short-term) memory, family members or other informants are often used as a primary source of history and to assist in decision making and negotiation of treatment plans. Family involvement in the clinical visit was viewed as important but time consuming. (Researcher, Hinton et al., 2007)

Availability of services

Many studies reported access to services as a reason to diagnose dementia. However practitioners from almost all studies discussed the inadequacy of services for people with dementia. Practitioners' perceptions of lack of or poor services meant they were

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less likely to diagnose dementia and communicate that diagnosis.

..... GPs interviewed indicated that the social services available were insufficient, inadequate, and complex, and that patients' families felt powerless, isolated, and in distress. (Researcher, Lahjibi-Paulet et al., 2012)

Almost all complained about the extremely limited services—such as community based nursing care, day-care, or respite—that were available to support care in the home. Although most communities had some form of long-term care available, only one had a dedicated dementia-care unit. (Researcher, Teel, 2004)

Interestingly, practitioners in a few studies said that having a diagnosis of dementia may make it more difficult to access services due to structural discrimination.

Three GPs suggested that having a diagnosis of dementia might actually make it more difficult for some patients to access medical services because of the stigma of dementia and a shortage of dementia specific services (Researcher, Hansen et al., 2008)

Cultural norms in relation to dementia

Stigma in the community

Stigma around dementia made practitioner's more reluctant to initiate, diagnose and communicate the diagnosis because of concerns about the implications of having a label of dementia, including implications for the family. Associated with this idea of

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stigma is that the label 'dementia' evokes the image of someone with later stage dementia with significant impairment and high dependency. Practitioners were concerned about the impact of the diagnosis on the person with dementia's self-concept. They were worried that people with labels of dementia may be treated negatively by others within society. Practitioners in a few studies were also concerned that people with dementia are discriminated against within the health and social care system.

"To a mildly demented person, "Alzheimer's" means "people sitting in a chair in the nursing home, being fed", and that's the only image that that word is going to have. And so, for that person, that word would be devastating." (Specialist, Kissel and Carpenter, 2007)

GPs highlighted their awareness of devaluation through their perception of people with dementia not being particularly valued by society and not being considered valuable partners for social interaction... They recounted how the devaluation of people with dementia might take the form of derision, including gestures such as rolling the eyes and tapping the head.(Researcher, Gove et al., 2016)

In contrast to the impact of stigma delaying diagnosis and softening their communication, practitioners talked about increased general awareness about dementia because of media coverage. This means that patients and families may know more about dementia though this may not all be accurate, and may be requesting diagnosis and treatment.

“In the last 5 to 10 years, there has been so much in the media about it, that...they are demanding the diagnosis so they can start up something and turn this person around”
(Primary Care Physician, Connell et al., 2004)

The label can produce emotional distress

Related to the notion of societal stigma was that of the self-stigma and emotional distress that being given a label of dementia may produce. Practitioners in many studies were concerned about the impact of the diagnosis on the patient’s psychological health. Interestingly this concept was discussed broadly rather than in relation to individual patient circumstances (i.e. identifying characteristics of patients who may be at greater risk of distress). Practitioners thought that the diagnosis may cause loss of hope, anxiety, and depression and could even lead to suicide.

“I’m very, very careful about um, destroying positive outlooks on life with the diagnostic label.” (GP, Dhedhi et al., 2014)

For patients, disclosing the diagnosis could be destructive, creating anxiety and provoking a depressive reaction to the “bleak outlook” (Health professional, Iliffe et al., 2003)

Common clinical practice

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Practitioners in a few studies referred to common clinical practices with regards to dementia as these aligned or contrasted with their individual practices. For instance they talked about how they interpreted guidelines on timely diagnosis of dementia within a 'best interests of patient' approach, discussed their medical training to only diagnose treatable conditions, and talked about dementia in the context of resisting the medicalization of ageing. In one study participants justified their own behaviour by describing a service culture of non-disclosure.

"Actually informing clients that they have dementia has never really been part of the culture...certainly you don't routinely tell people they have dementia." (Keightley and Mitchell, 2004)

"Dementia is one of those things—you tend to only look for the things that you can treat easily." (Boise et al., 1999)

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Who should give the diagnosis of dementia?

Some practitioners avoided having to give the diagnosis of dementia by referring to specialists, memory clinics or other services (such as aged care assessment teams in Australia). Other generalists felt strongly that it is their responsibility to give the diagnosis. In one study practitioners suggested that a family member could sometimes be the most appropriate person to give the person with dementia the news.

“I send them to a specialist on purpose. Announcing the diagnosis is precisely the moment when the presence of several people is necessary. It’s too violent for one person to tell another. I think it’s a good idea.”(GP, Lahjibi-Paulet et al., 2012)

‘I think it would be a horrible thing to be told by a specialist or a third party that you’ve never met or seen before. It would be far better for that information to have been given to a carer, fine—but, if the information is going to be given to the patient, you’d want it to be someone that knows the patient I think.’ (GP, Phillips et al., 2012)

Approaches to communicating the diagnosis

Practitioners described a range of approaches in communicating the diagnosis of dementia. What they said and the amount of information they conveyed depended on what they thought the person was ready to hear, and being sensitive to the needs of their patient and family. They described softening the diagnosis (by using terms such as ‘maybe’, euphemisms, and normalizing the symptoms), putting a positive spin or frame on information (such as by focusing the discussion on treatments and services), or having a formal spiel which normalizes the symptoms.

“We do not lie regarding the clinical findings; we just try to veil them” (Specialist, Karnieli-Miller et al., 2007a)

“... so I’ll kind of soft touch the diagnosis ... and focus more on their memory rather than

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saying you've got Alzheimer's." (Primary care physician, Connell et al., 2004)

Terms used when communicating the diagnosis

Some practitioners advocated using correct medical terms when communicating the diagnosis. However, practitioners in many studies disliked the term Alzheimer's, some preferring to use the term dementia.

"I may not say "Alzheimer's disease", but I'll say "dementia". And I'll fully explain what I mean by that, so that I'm giving the correct definition of what Alzheimer's disease is, but I may call it dementia." (Specialist, Kissel and Carpenter, 2007)

Practitioners used euphemisms most commonly describing problems with memory (e.g. memory problems, memory loss' or the brain (brain ageing, brain shrinking, loss of brain cells) rather than naming the disease. Some considered having described the symptoms and offered treatments sufficient in terms of giving the patient the diagnosis.

I say "you have a disease of the blood vessels in the brain, and that is why you have these problems" or "you have a problem of metabolism ... and that is why you have trouble remembering". I tell them all of the deficiencies they have ...; ...I don't say 'yes, it is definitely Alzheimer's". I believe that I give them a full disclosure without using the words they fear most (Specialist, Karnieli-Miller et al., 2007a)

"I don't think I ever used the term dementia with her...I wouldn't say that I didn't give her

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a diagnosis, but I didn't give her a label. It's not the term in itself, it's what does it mean to this patient?" (GP, Dhedhi et al., 2014)

Who is told the diagnosis of dementia?

Some practitioners preferred to tell the person with dementia and the family the diagnosis together. A few stated that for people with early dementia they preferred to tell the patient first and let them decide when and how to tell their family. However, practitioners in many studies gave more information about the diagnosis to family than the person with dementia. With family, practitioners were more likely to use the terms dementia or Alzheimer's disease, talk about prognosis, and management, and planning ahead.

*"I use the term Alzheimer's a lot more with family members and not with the patient."
(Primary care physician, Connell et al., 2004)*

GPs were more likely to disclose the diagnosis, use medical terms and discuss the likely progression with the family carers than with the person himself or herself when discussing the illness. (Researcher, Downs et al., 2002)

Discussion

Pooled analysis found that 34% of GPs and 48% of specialists usually/routinely tell persons with dementia their diagnosis, and 89% of GPs and 97% specialists usually/routinely tell families the diagnosis. This means that over half of persons with a diagnosis of dementia are not told their diagnosis. Euphemistic terms such as 'memory problems' are more often used to describe dementia than medical terms, particularly with people with dementia. Practitioners' decision to diagnose and tell the diagnosis of dementia are influenced by their own beliefs regarding dementia, and their confidence in diagnosis and communication, the awareness and circumstances of the patient, and medical practice and societal norms and the health and care social system in which they practice.

Who should be giving the diagnosis of dementia? This review found that some general practitioners favoured giving the diagnosis themselves, and others favoured specialists giving the diagnosis. These data suggests that specialists are more likely to communicate the diagnosis, and use medical terminology, this may be because specialists may be more likely to see patients with awareness of their symptoms seeking help. Australian clinical guidelines recommend that the diagnosis of dementia is made by specialists, (Clinical Adaptation Committee, 2016) and the UK national dementia plan suggests that primary care should refer those with worrisome symptoms to get a diagnosis (Department of Health UK, 2013). More discussion is needed about how primary care practitioners and specialists work together (possibly in a shared care model) in diagnosing and managing dementia. Even if specialists make the diagnosis, general practitioners still have a critical role in recognising possible dementia cases and

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making referrals, which necessitates being able to have conversations about the possibility of the diagnosis of dementia.

The behaviour of practitioners may have unintended negative consequences on patients and family. Secrecy, practitioners' lack of confidence with regards to treatment benefits, and directing of information towards family may exacerbate self-stigma, and feelings of loss of control and hopelessness in persons with dementia (Read et al., 2016, Low et al., 2017).

Stigma in the community, and attitudes of practitioners affected if, and how, the diagnosis was communicated. Practitioners were more likely to tell the diagnosis to those who wanted to know, and were concerned about the distress that persons with dementia may experience when given the diagnosis, and that they may be discriminated against by society or the health care system. Public campaigns to decrease stigma in relation to mental illness result in increases in help-seeking (Henderson et al., 2013) and improvement of attitudes (Gronholm et al., 2017) and such campaigns may be needed for dementia. Patients are also increasingly seeking out medical information on the internet (McMullan, 2006). Increased knowledge and decreased stigma may empower consumers to demand dementia investigation, diagnosis and treatment.

We identified only one intervention study with the primary aim of improving communication of dementia and this was unsuccessful in changing practice (Eccles et al., 2009), this shows that more intervention research is needed. Changing practitioner behaviour with regards to dementia diagnosis and management is challenging. For

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instance the UK government's efforts to increase timely diagnosis of dementia through practitioner education, financial incentives for diagnosis and management, and introduction of specialist diagnosis services (memory clinics) showed no effect on incidence of dementia over 14 years (Iliffe and Wilcock, 2017).

One step in designing complex interventions is to identify and address barriers to behaviour change (French et al., 2012). The individual and structural barriers identified in this review could be addressed through a multicomponent approach including:

- a) Development of guidelines on how to communicate a diagnosis of dementia.
Such guidelines have been developed for cancer (Rodin et al., 2009, National Breast Cancer Centre, 2012)
- b) Training to improve practitioner skills and confidence in diagnosis and communication of the dementia. Training on making a diagnosis of dementia should be accompanied by training on the need to communicate the diagnosis to the patient as well as their family, and how to appropriately convey the information (e.g. as a series of discussions). The communication of diagnosis component could be informed by successful programs to improve cancer communication (Pham et al., 2014, Baile et al., 2000).
- c) Social marketing campaign to address stigma in the community, particularly targeting older people
- d) Provision of therapeutic services for mild dementia could add weight to early diagnosis being a beneficent action and allow practitioners to act on the diagnosis and offer hope. Cognitive stimulation therapy is one such treatment (Bahar-Fuchs et al., 2013), however research is needed to further demonstrate

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the efficacy of treatments such as cognitive rehabilitation, speech pathology, acquired brain injury style rehabilitation and occupational therapy for mild dementia.

- e) Reducing structural barriers such as ensuring that practitioners can be sufficiently reimbursed for time spent managing dementia. Another strategy may be involving practice nurses in the dementia diagnosis and management so that persons with dementia and families get the time they need within the financial reimbursements available.
- f) Ensuring that specialist dementia diagnosis services are accessible in all geographical areas, rural areas could be serviced through telehealth which has been shown to provide valid diagnosis (Martin-Khan et al., 2012)
- g) A dementia registry may encourage diagnosis by tracking performance against standards (Religa et al., 2015)

A caveat in designing an intervention is that this review only takes into account the viewpoints of health practitioners; the viewpoints of persons with dementia and their carers also need to be considered (e.g. (Low et al., 2017). People with dementia and their carers should be part of the design team for interventions on communicating a dementia diagnosis.

This review was limited by the characteristics and methodologies of included studies and methodologies. Making and communicating a diagnosis were treated in quantitative studies as two distinct consecutive procedures. However, our qualitative suggests that practitioners often view these as intertwined processes. Not all quantitative papers asked about factors of interest in this review, and the diversity of methodology meant

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that not all data could be pooled. We do not know whether the broad range in responses were because of true differences between samples, differences in methodology in the way the question was worded or a combination of the two. In addition, some quantitative papers did not specify in the question to whom the diagnosis of dementia was told. When not specified we assumed that the response referred to persons with dementia, however this could have been interpreted by practitioners as having told either the patient or family. Longitudinal qualitative studies combining observation of clinical conversations and interviews with practitioners, patients and family (Karnieli-Miller et al., 2012a, Karnieli-Miller et al., 2012b) may aid further understanding of how the diagnosis of dementia is communicated and the impact of different communication styles on the experiences of people with dementia and their families.

The majority of studies came from developed nations. The rate of dementia communication may be lower in developing countries, where practitioners may have a more paternalistic stance, and where patient autonomy are not as strongly emphasized (Matusitz and Spear, 2015).

Data extraction and interpretation were subject to our own experiences and assumptions as researchers interested in the process and barriers to communicating a diagnosis of dementia. We attempted to be objective, and our authorship team came with multiple viewpoints including a member who is a specialist in diagnosis (HB), who has received a diagnosis (KS), who is familiar (LFL) and less familiar (MM) with the diagnostic and support processes.

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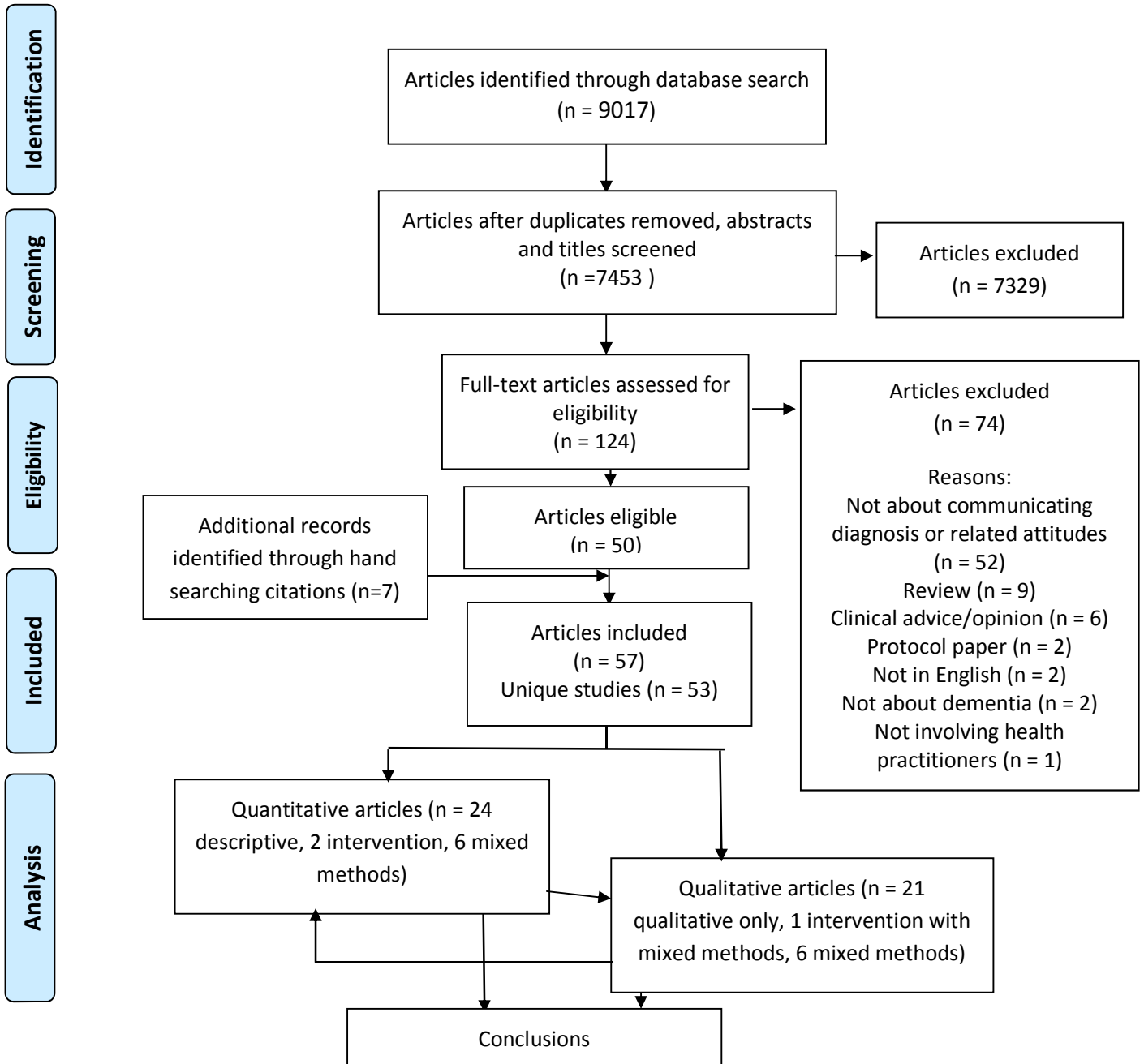
One strength of the paper is the sequential mixed methods systematic review approach which allowed us to describe practitioner behaviour using quantitative data, as well as try to understand the influences on this behaviour using qualitative data. This enabled production of results that are generalizable yet offer a nuanced understanding of how and why the dementia diagnosis is communicated.

Conclusion

It is a worldwide problem that most people with dementia are not explicitly told their diagnosis. This could be considered unethical practice, and a breach of human rights. Without a diagnosis people are being denied their right to information about their condition and prognosis, to drug treatments and non-pharmacological interventions which may promote their quality of life, and to participate in discussions and express their wishes for the future through wills and advance care directives while still able.

It has been over 20 years since the first paper included in this review was published and there appeared to be little change in whether and how a diagnosis dementia is communicated across this time. This is despite greater awareness of dementia in the community because of media and health policy focus, increased accessibility of information on dementia on the internet, and research advances in neuroimaging and diagnosis (Gauthier et al., 2013). Well-designed multicomponent intervention programs are required to improve how a diagnosis of dementia is communicated, these may also contribute to initiatives to improve timely diagnosis of dementia.

Figure 1. Flow chart indicating inclusion of articles in the review

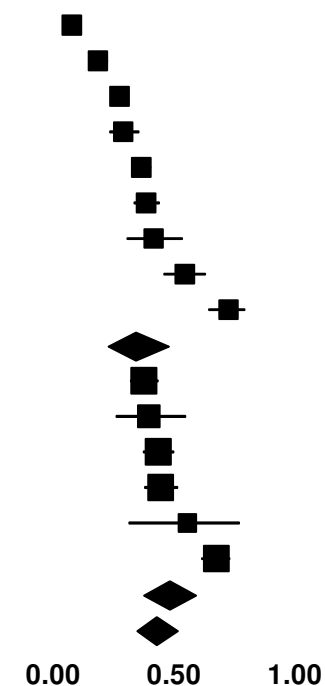


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Figure 2. Random effects pooled data on the proportion of practitioners (event rate) who usually, routinely always tell people with dementia their diagnosis

<u>Group by</u> Participants	<u>Study name</u>	<u>Total</u>	<u>Event rate</u>	<u>Lower limit</u>	<u>Upper limit</u>
GP/PCP	Somme 2013	87 / 1058	0.082	0.067	0.100
GP/PCP	Cahill 2006, 2008	68 / 359	0.190	0.153	0.234
GP/PCP	Cantegreil-Kallen 2005	172 / 616	0.280	0.246	0.317
GP/PCP	Caruna-Pulpan 2014	57 / 193	0.295	0.235	0.363
GP/PCP	De Lepeleire 2004	193 / 521	0.370	0.330	0.412
GP/PCP	Vassilas 1998	110 / 281	0.390	0.335	0.448
GP/PCP	VanHout 2006	27 / 64	0.420	0.306	0.543
GP/PCP	Downs 2002	63 / 114	0.550	0.458	0.639
GP/PCP	Cody 2002	88 / 121	0.730	0.644	0.802
GP/PCP			0.342	0.227	0.479
Specialist	Rice 1994	90 / 238	0.380	0.321	0.443
Specialist	Johnson 2000	16 / 40	0.400	0.262	0.557
Specialist	Clafferty 1998	92 / 209	0.440	0.374	0.508
Specialist	Raicher 2007	81 / 181	0.450	0.379	0.523
Specialist	Gillard 1996	8 / 15	0.560	0.315	0.779
Specialist	Tarek 2009	147 / 216	0.680	0.615	0.739
Specialist			0.483	0.375	0.591
Overall			0.429	0.346	0.515

Event rate and 95% CI



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Figure 3. Random effects pooled data on the proportion of practitioners (event rate) who usually, routinely always tell family the dementia diagnosis

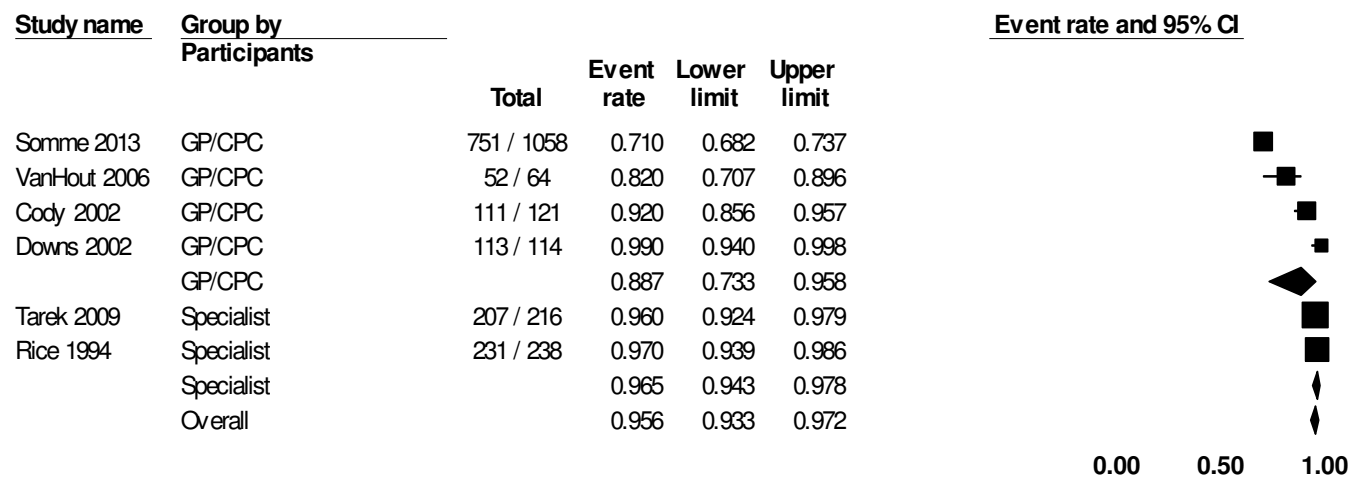


Table 1. Characteristics of descriptive quantitative, intervention and mixed methods studies

Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
Quantitative descriptive studies							
Cantergreil-Kallen 2005	France	To examine whether and how a diagnosis of AD is disclosed by GPs and what information is discussed with the patient	Convenience sample from two different networks of GPs	39%	616 GPs Demographics not given	Postal survey	25%
Caruana-Pulpan 2014	Malta	To explore how GPs manage diagnosis, communication and pharmacological management of people with dementia.	Full sample of all registered GPs in Malta	54%	193 GP 72% male	Postal survey	75%
Clafferty 1998	Scotland	To explore doctors' normal practice regarding communication of a diagnosis of dementia	Full sample of all consultant psychiatrists registered with the NHS as working in Scotland	76%	216 consultant psychiatrists Demographics not given	Postal survey	50%
Cody 2002	United States	To determine PCPs' approach to diagnosis, referral and management of dementia	Volunteer sample from professional meeting, and undescribed sample from PCPs from state	15% from postal survey	142 PCPs 79% male 64% group practices 51% urban practices	Written survey (completed at professional meeting or by post)	75%
De Lepeieire 2004	Belgium	To explore GPs' normal practice regarding communication of a diagnosis of dementia	Random sample from list of GPs working in two cities	60%	521 GPs Demographics not given	Postal survey	100%
Fortinsky	United	To explore PCPs' self-	Random sample	27%	422 PCPs	Postal	75%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
2010	States	reported approaches to management of dementia including barriers to support	of registered physicians in one state, and full sample of PCPs in second state		65% male 19% 25-39 yrs 59% 40-54 yrs 22% 55 or older	survey	
Fox 2014	United Kingdom	To explore the low rate of dementia diagnosis by GPs and to identify what is needed to support GPs to meet government targets for dementia diagnosis	All GPs within 4 clinical commissioning groups in two regions	28%	113 GPs Demographics not given	Online survey	75%
Gaboreau 2014	France	To identify the factors influencing dementia screening by GPs	All GPs in two regions	27%	493 GPs n=493 67% male Age: 50 \pm 8 54% group practices	Electronic or paper based survey	50%
Gilliard 1996	United Kingdom and Ireland	To understand how much information is shared with people with dementia	All consultants in charge of memory disorders clinics in the British Isles	80%	16 consultants Demographics not given	Postal survey	50%
Johnson 2000	United Kingdom	To examine current practice and attitudes among specialist staff towards communication of a diagnosis of AD	All doctors working in old-age psychiatry and geriatric medicine in hospitals within region.	73%	25 geriatricians 15 old age psychiatrists	Postal survey	100%
Jones 2010	Europe	To determine the attitudes of caregivers, physicians, general public and payers	From an internet market research sample	Not given	500 physicians 100% <70 years	Online survey	25%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
Margiotta 2002	Italy	towards AD and dementia To evaluate views and beliefs of physicians on diagnosis, therapeutic, ethical and legal issues arising during the management of older people with dementia	All general physicians, geriatricians, neurologists and psychiatrists working in a province	17%	155 doctors: 58% PCPs 20% geriatricians 16% psychiatrists 11% neurologists 51% male 55% >50 years 41% 30-50 years 4% <35 years	Postal survey	25%
Martinez-Lage 2000	France, Germany, Italy, Spain and the UK	To assess the attitudes and perceptions of physicians towards diagnosis and treatment of AD, caregivers and families with AD and role of government in AD	Details not given	Not given	250 generalists: 88% GPs 2% internists 6% hospital general physician 250 specialists: 78 % neurologists 6% geriatricians 4% psychiatrists 4% psychogeriatricians	Online survey	0%
McIntosh 1999	Scotland	To explore perceived roles, attitudes and anxieties of GPs and nurses working with people with dementia and to determine if providing dementia care is a stress provoking experience	Health practitioners attending training around Scotland	98%	Age 25-69 years 785 GPs and nurses: 38% GPs 62% nurses 25% male	Written survey	75%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
OlafsdOttir 2001	Sweden	To identify reasons for low detection rate of dementia in primary care services To explore attitudes and knowledge of dementia among general practitioners	All GPs and GP registrars in one county.	67%	153 GPs 63% male Mean age: 47 years	Postal survey	100%
Raicher 2008	Brazil	To investigate practice and attitude of specialist physicians towards AD diagnosis	All members of specialists societies' electronic mailing lists	19%	181 specialists: 36% neurologists 22% geriatricians 41% psychiatrists 68% male Age: 45 \pm 11 (28-74)	Electronic survey	50%
Renshaw 2001	United Kingdom	To investigate GPs' views on early diagnosis of dementia	Practices selected using maximum variation sampling	55%	1005 GPs Demographics not given	Postal survey	25%
Rice 1994	United Kingdom	To explore approach to communication of diagnosis of dementia to patients and family members among psychiatrists	All UK members of Old Age Section Consultants	79%	259 old age psychiatrists Demographics not given	Postal survey	50%
Rubin 1987	United States	To explore PCPs knowledge of dementia	Random sampling with replacement drawn from list of all PCPs in county in the specialities of family medicine or internal	Not given	50 PCPs: 68% family practitioners 32% general internists 88% male Age: 43 \pm 12 (29-69) 50% group practice	Telephone interview	100%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
medicine.							
Somme 2013	France	To identify clinical practices, challenges and training needs of GPs in relation to dementia care	Random selection of GPs from the national database	54%	1058 GPs 69% male 12% <40 yrs 30% 40-49 yrs 45% 50-59 yrs 14% >50 yrs	Telephone interview	75%
Tarek 2009	Belgium	To explore neuropsychiatrists and neurologists opinions regarding communication of a diagnosis of AD	All neurologists and neuropsychiatrists on electronic hospital database.	44%	250 specialists: 42% neurologists 58% neuropsychiatrists 66% male Age 11% < 30 yrs 30% 31-40 yrs 29% 41-50 yrs 19% 51-60 yrs 12% >60 yrs	Postal survey	75%
Turner 2004	United Kingdom	To measure GPs knowledge, confidence and attitude towards diagnosis and management of dementia in primary care	All GP practices in selected regions that used electronic medical records invited to participate in intervention study	28% of 124 practices participated	127 GPs 66 male Age: 43 \pm 8 87% group practices	Postal survey	50%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
Van Hout 2006	Netherlands	To describe what GPs tell people who appear to have dementia and their caregivers after assessment and to estimate the number of incorrect communications	Convenience sampling	Not given	64 GPs 79% male Age 45 \pm 8 (34-64)	Paper based survey	75%
Vasillas 1998	United Kingdom	To explore GPs' practice regarding communication of diagnosis to patients with terminal cancer or dementia	All GPs in region invited	76%	281 GPs 69% male	Postal survey	75%
Quantitative intervention studies							
Eccles 2009	United Kingdom	To explore in a randomised controlled trial the impact of one theory based and two pragmatic pencil-and-paper interventions on the intention to (i) find out what the patient already knows or suspects about their diagnosis (ii) using explicit terminology when discussing diagnosis (iii) exploring what the diagnosis means to the patient	Members of Old Age Mental Health Teams in England	87% for teams 58% for individuals	948 (baseline) 644 (follow-up) health professionals from old age mental health teams 10% doctors 47% nurses 19% allied health 9% social work or care managers 2% manager/team leaders 12% support workers	Postal survey, baseline survey, written intervention immediately followed by follow-up survey	25%
Galvin 2012	United States	To evaluate in a pre-post mixed methods design the impact of a 3-day educational program on health professionals' dementia knowledge, confidence in providing care and practice behaviours	All rural health professionals enrolled in dementia training program	100%	146 health professionals 48% physicians 23% advance practice nurses & physician assistants 4% allied health 48% male Age: 46 \pm 11	Paper based survey Pre and post testing with 3 and 12 month	20%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
follow up							
Mixed methods studies							
Cahill 2006, 2008	Ireland	To investigate GPs attitudes and practices in relation to screening, diagnosing and communicating a dementia diagnosis To detail the service needs of GPs when attempting to diagnose dementia in relation to (i) training (ii) access to diagnostic resources (iii) access to specialist services	Random sample from a national database of GPs Convenience sample of rural GPs (n=7) for focus group	50%	300 GPs 61% male Age: 45 \pm 11 (27-88) 63% group practices 79% urban practices	Postal survey including open ended questions, focus groups	64%
Downs 2000, 2002	United Kingdom	To assess GPs' views and practices regarding dementia diagnosis and management To examine what GPs tell people with dementia and their families about dementia	Volunteer sample of GPs attending dementia training	98%	2000 paper: 278 GPs 58% male Age: 41 \pm 9 94% group practices 69% urban practices 2002 paper: 114 GPs 58% male Age: 42 \pm 8	Written survey including open ended questions	75%
Kaduszkiewicz 2008a, 2008b	Germany	To explore the relationship between physicians' self-estimated competence with respect to care of patients with dementia and their attitude and approach to this care and to compare GPs and specialists in care of people	All GPs in dementia network and to a random samples of GPs and specialists	54% for GPs 40% for specialists	211 GPs 96 Specialists 62 %male	Postal survey	64%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Appraisal Tool Score
		with dementia. To investigate differences between GPs and specialists (neurologists and psychiatrists) towards communication of a diagnosis of dementia	working in six towns and surrounding areas.				
Milne 2000, 2005	United Kingdom	To investigate attitudes of GPs towards early diagnosis of dementia To compare GP attitudes towards early diagnosis of dementia in 1997 and 2001	All GPs in one health authority	59% time 1, 29% time 2	182 GPs time 1 93 GTs time 2 Demographics not given	Postal survey	45%
Pathak 2015	Nepal	To examine GPs' knowledge, practices and obstacles towards diagnosis and management of dementia	All GPs in all public hospitals in city.	89%	380 GPs Demographics not given	Written survey	45%
Van Hout, 2000	Netherlands	To explore GPs' perceptions of their tasks, their practice and obstacles in diagnosing and managing dementia	"Normal" GPs randomly selected from list of all GPs in the region "Expert" GPs identified based on publicatio	Not given	28 GPs Demographics not given	Focus groups, written survey	45%

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Author, year	Setting	Aim	Sampling	Response rate	Participants Gender Mean age \pm SD (range) Practice characteristics	Data Collection	Mixed Methods Apprais al Tool Score
			n or service developm ent work in dementia				

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Table 2. Characteristics of qualitative studies

Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Boise 1999	United States	To investigate how PCPs approach the diagnosis of dementia To identify barriers to diagnosis in primary care	Purposive sampling through professional organisations, conferences and networks used to recruit for diversity of clinical settings and experience with dementia.	77 PCPs: 45% specialising in family practice 54% specialising in internal medicine	Focus groups Thematic analysis	Assessment process involves four stages: (i) Initial awareness (ii) Clinical workup/ assessment (iii) Determination and charting of diagnosis (iv) Communication of the results to patient/family Barriers to dementia diagnosis included: (i) Symptom recognition (ii) Lack of knowledge of assessment procedures (iii) Physician attitudes (iv) Practice constraints Family members exercise a significant amount of control over diagnosis	50%
Connell 2004	United States	To examine the attitudes of caregivers and physicians toward assessing and diagnosing dementia including communication of diagnosis	Convenience sample recruited by Alzheimer's Disease Centres 1	39 physicians: Specialities: 34% family medicine 53% internal medicine 13% geriatrics 66% male	Focus groups Thematic analysis	Physicians reported <ul style="list-style-type: none"> • Feeling pressured by family members to make diagnosis • Lack of time • Difficulty maintaining balance between keeping confidentiality and keeping family informed 	50%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Dhedhi 2014	United Kingdom	To explore GPs' understanding of the concept of timeliness as it relates to diagnosis of dementia	Convenience sampling from academic department of primary care	Age: 41 (28-54) 7 GPs 3 Male Age 30-65 yrs	Interviews Narrative analysis	<ul style="list-style-type: none"> • Diagnosis is not a singular event – it is an unfolding process experienced in the context of ongoing relationship with person with dementia / family • Determining the right time for diagnosis involves weighing up costs and benefits of formal diagnosis for person and family • GPs differentiate between making the diagnosis and disclosing the diagnosis • Formal diagnosis was seen as changing the future and so GPs were reluctant to rush towards this diagnosis 	50%
Dodd et al. 2014	United Kingdom	To compare participants' experiences of primary care led dementia care services with traditional secondary care based memory services	GPs from primary care led dementia services invited by email Health professionals from memory clinics invited during team	10 GPs 8 professionals from memory clinics 6 male	Interviews by peers Thematic analysis	<ul style="list-style-type: none"> • GPs lack confidence to make independent diagnosis of dementia • Collaboration between GP and memory nurse is perceived positively and supports diagnosis • Patients and caregivers do not perceive differences in quality between primary care led dementia service and 	100%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection, data analysis	Key results	Mixed Methods Appraisal Tool Score
			meetings			<p>secondary memory clinic</p> <ul style="list-style-type: none"> • GPs are restricted to short appointments with limited opportunity to consult with others • GPs are less focused on providing an exact diagnosis and some may be reluctant to use terms dementia • Limited follow up care is provided by either primary care led dementia services or secondary memory clinics 	
Gove 2016	England	To explore how GPs' perceptions of dementia relate to current conceptualisations of stigma and to identify if GPs feel that stigma affects timely diagnosis	Purposive sampling from a random selection of GPs in the north of England	<p>23 GPs</p> <p>57% male</p> <p>Age 29-62 years</p> <p>83% urban practices</p> <p>91% group practices</p>	<p>Telephone interviews</p> <p>Thematic analysis</p>	<ul style="list-style-type: none"> • GPs perceive that stigma related to dementia is reducing but is still present and as a result avoid using medical terminology when discussing potential diagnosis • GPs reported fear and anxiety that they too could have dementia in the future. This anxiety led to an emotional distancing from people with dementia • GPs perceived that the diagnosis of dementia leads to a devaluation of the person by others, society in general and can result in the 	100%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
						<p>person with dementia experiencing discrimination</p> <ul style="list-style-type: none"> • While GPs acknowledged the need for timely diagnosis they also reported experiencing difficulty in approaching diagnosis and concerns about the impact of the label for the person with dementia and their family 	
Hansen 2008	Australia	<p>To explore how Australian GPs described their experiences of diagnosing dementia</p> <p>Also considered GPs views on early diagnosis and explored potential barriers to early diagnosis</p>	Purposive and snowball sampling for diverse group of GPs	<p>24 GPs</p> <p>54% male</p> <p>75% urban practices</p>	<p>Focus groups & interviews from 3 separate studies</p> <p>Thematic analysis</p>	<ul style="list-style-type: none"> • Diagnosis of potential dementia is an involved process which includes consideration of the patients context; formal screening tools were not identified as particularly helpful • Early diagnosis of dementia is not particularly important and may cause harm • GPs rarely made use of medication to manage dementia • Formal diagnosis is more likely to be sought when the GP perceives that this will be useful to the patient/family • Determining if and when to make a diagnosis can 	50%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Hinton 2007	USA	To explore how practice constraints influence health care provided to people with dementia and their families particularly in relation to behavioural aspects of care	Recruited from physicians of older Latino carers participating in another study.	40 PCPs Specialty: 55% family practice 40% internal medicine 5% geriatrics 88% male Age: 38% 25—45 yrs 58% 45-65 yrs 5% 66-80 yrs	Interviews Thematic analysis	generate conflict between GP family members and person with dementia <ul style="list-style-type: none"> • Difficult to offer comprehensive care for people with dementia in typical time allocated for consultation • Re-imburement policies do not account for the complexity of caring for people with dementia and their families • Access to specialist services is needed (due to low levels of knowledge and confidence among the PCPs) but is not always readily available • Lack of access to interdisciplinary team hinders provision of quality care 	75%
Iiffe 2003	United Kingdom	To explore the perspectives of primary care professionals regarding early diagnosis of dementia	Participants attending one-day workshops on dementia held across the UK	990 primary care professionals : 25% GPs 27% nurses 49% other health	Nominal Group Technique	<ul style="list-style-type: none"> • Early diagnosis has both advantages and risks – diagnosis is associated with reduced uncertainty, prognosis and support but also brings about anxiety, labelling and stigma • The value of screening for dementia was contested 	55%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
				professionals)		<ul style="list-style-type: none"> • Most groups were uncertain about how to access specialist services and felt local services were unable to adequately support families and people with dementia • Early diagnosis programs were perceived as having resource implications for GP services • Disagreement exists regarding whether or not GPs are reluctant to diagnose dementia with some suggesting that GPs are more reluctant to disclose the diagnosis. There was some suggestion of avoidant behaviour around diagnosis and communication with GPs referring to the need for specialist input in order to make diagnosis 	

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Karnieli-Miller 2007	Israel	To explore physician's attitudes, challenges and communication approaches towards communication of the diagnosis of AD in clinical practice,	All three neurologists working in a cognitive neurology unit were invited	3 neurologists	Interviews & observation Thematic analysis	<ul style="list-style-type: none"> • Approach to communication of diagnosis is shaped by anticipated reaction of patient • Physicians use euphemisms, tentative language and delaying tactics to avoid direct communication • Encounters between clinicians and people with dementia are brief- this avoids having to provide large amounts of detail • Physicians rarely checked understanding of the information provided • Physicians move rapidly from providing diagnosis to (i)offering reassurance or (ii) providing management options 	50%
Karnieli-Miller 2012	Israel	To analyse first time encounters in a memory clinic including behaviours, perceptions and experiences of clinicians, carers and people receiving a	Out-patient memory clinics patients recruited through convenience sampling, 25 encounters reported purposively chosen for	6 physicians	Observation & semi-structured interviews Grounded theory analysis	<ul style="list-style-type: none"> • Communication typically involves 2 of the 3 members of the triad (patient, companion and doctor) • The third person tries to be actively involved in the conversation but with limited success • Communication during diagnosis moves from 	50%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
		diagnosis of dementia	maximum variation			talking with the patient to talking about the patient or ignoring the patient	
Keightley 2004	United Kingdom	To investigate what factors influence mental health professionals when deciding whether or not to disclose diagnosis to people with dementia	Theoretical sampling was used to identify most suitable participants from convenience sample of three multidisciplinary mental health teams for older people	5 Community Psychiatric Nurses 2 Clinical psychologists 4 male	Semi-structured interviews Grounded theory analysis	<ul style="list-style-type: none"> Professionals reported uncertainty whether or not people with dementia would want to know their diagnosis This led professionals to avoid diagnosis communication for fear of causing harm Professionals experienced strong sense of hopelessness and helplessness regarding dementia This view of dementia supported professionals to adopt a protective stance towards people with dementia 	100%
Kissel-2007	United States	To explore physicians opinions about how to disclose a diagnosis of dementia	Physicians working in an Alzheimer's Disease Research Center were invited to participate	10 physicians: 50% neurologists 40% geriatrics 10% geriatric psychiatrists 6 male	Semi-structured interviews Grounded theory	<ul style="list-style-type: none"> Although physicians agreed that the diagnosis should be communicated there was variation in what was understood by communication Approaches to communication was case specific and involved modification to who was involved, what language was 	50%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
						used and what topics were covered	
						<ul style="list-style-type: none"> Approaches to communication are guided by the physicians clinical reasoning which includes evaluation of care planning, family dynamics, patient preferences and professional obligation to communicate clear information within a short consultation time 	
Lahjibi-Paulet 2012	France	To explore the attitudes and perceptions of GPs in France toward diagnosis and management of AD	Random selection of GPs working as supervising instructors at a university medical school who also worked in private practice	20 GPs 16 male Mean age: 49 (40-62)	Semi-structured interviews Thematic analysis	<ul style="list-style-type: none"> Stigma and a sceptical attitude towards the efficacy of drug treatments for AD mean that AD is seen as a disease without medical treatment GPs primary goal is to maintain patient autonomy and ability to live at home GPs see specialists as providing an alternative mechanism to deliver 'bad news' regarding diagnosis 	75%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Moore 2013	Sweden Ireland	To explore attitudes of GPs in Ireland and Sweden towards diagnosis and communication of dementia to patients, training in dementia and post-diagnostic support services available to GP, and the extent to which dementia is perceived as stigmatising	Combination of convenience and snowball sampling	9 GPs 3 male Age: mean 53 6 urban practices 8 group practices	In-depth interviews Thematic analysis	<ul style="list-style-type: none"> • While recognising that diagnosis of dementia is important GPs were not proactive in making a diagnosis • Most GPs were reluctant to make a diagnosis, relied on patients or family members to initiate the diagnostic process and avoiding using the term dementia • Swedish GPs had received more training and had access to more community support services than Irish GPs 	75%
Murphy 2014	Australia	To explore GPs' practice relating to diagnosing and managing dementia and to develop a theoretical understanding of why this practice was or was not consistent with evidence based guidelines	Random sample stratified by rural/metropolitan geography drawn from GP register restricted to one state	30 GPs 18 male 13 urban practices 19 group practices	Semi-structured interviews Content and thematic analysis	<ul style="list-style-type: none"> • Barriers to adherence to clinical guidelines relating to assessing co-morbid depression include beliefs regarding the need for validated tools to assess co-morbid depression, discomfort caused by limited training and confidence in using validated tools, limited awareness of the need for assessment of depression • Facilitators to adherence to clinical guidelines for cognitive assessment 	50%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection, data analysis	Key results	Mixed Methods Appraisal Tool Score
						included awareness of the need for formal cognitive assessment, skills and confidence in using validated tools, having adequate time and resources to complete the assessment.	
Peel 2015	United Kingdom	To explore if the absence of explicit terminology during the communication of diagnosis is problematic	Memory clinic setting, sampling not described	Clinicians of 15 people attending a memory clinic Demographics of clinicians not given	Observations Conversation analysis	Use of particular terms during the communication of diagnosis of dementia does not influence the extent to which the communication is sensitive and responsive to patient and carer needs	75%
Phillips 2012	Australia	To explore GPs' perceptions of the barriers to disclosing a diagnosis of dementia	GPs participating in a 12 month dementia training intervention were invited to participate	45 GPs Demographics not given	Semi-structured interviews Thematic analysis	<ul style="list-style-type: none"> • GPs lack confidence in correctly diagnosing dementia and preferred referral to a specialist to confirm diagnosis • Stigma associated with dementia and influenced use of the term • GPs often used alternative terms when diagnosing dementia to soften the impact • The communication process was guided by the severity of dementia and GPs preferred 	75%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
						to discuss diagnosis with the patient when family/carers were present	
Pimlott 2009	Canada	To explore challenges experienced by family physicians in providing dementia care	Family physicians practicing at university affiliated clinics involved in a previous chart audit study were invited to participate	18 family physicians 7 male	Focus Groups Thematic analysis	<ul style="list-style-type: none"> Physicians had concerns about diagnosing dementia and expressed strong desire for specialist verification of diagnoses due to complexity of dementia Short consultation times meant physicians were unable to complete in-depth assessment in 1 visit however this allowed a gradual approach to diagnosis which was seen as beneficial Family members were seen as potentially identifying early symptoms or possibly downplaying these symptoms and thereby delaying diagnosis 	75%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
Prins 2016	The Netherlands	To explore GPs' views on current role in diagnosing dementia, reasons for referral to specialist care and perception of future diagnostic role of GPs	Purposive sampling	18 GPs 5 male Mean age: 52 (35-64) 14 urban practices 15 group practices	Semi-structured interviews Thematic analysis	<ul style="list-style-type: none"> • Current role in diagnosis is limited to identifying cognitive problems and determining the need for referral to specialist care • Referral to specialist services was likely to be made if the patient/family requested it or if the GP perceived that the specialist services would influence treatment outcomes • GPs typically did not refer older patients or those whose dementia appeared to be progressing slowly to specialist services • GPs would like to have a more prominent role in diagnosing dementia 	75%
Robinson 2008	Australia	To explore views about dementia diagnosis from the perspective of family carers, health professionals and dementia service personnel	Purposive sampling of participants with roles in management of people with dementia	7 GPs 20 Community nurses 23 Home carers 18 Residential aged care facility staff 16 Aged care assessment	Focus Groups Thematic analysis	<ul style="list-style-type: none"> • While the benefits of formal diagnosis are recognised the term dementia is associated with negative imagery and stigma • GPs were identified as central to the diagnosis process but have inadequate diagnosis and treatment options • Health professionals favour a gradual diagnostic process 	75%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
				team		<ul style="list-style-type: none"> Dementia specific services were not available without formal diagnosis 	
Teel 2004	United States	To explore primary care providers' experiences of diagnosis and treatment of dementia	All PCPs working in non-metropolitan areas of state were invited by post.	17 Physicians 2 Nurse practitioners 15 male Mean age: 51 (31-67)	Semi-structured interviews Constant comparative analysis	<ul style="list-style-type: none"> Time from onset of symptoms to diagnosis and placement in long-term care was variable and depended on family resources and support available Family members could either accelerate the process of diagnosis by proactively seeking help with early symptoms or could delay the process if they minimised early symptoms or attributed cognitive changes to ageing processes Family members' perception and negative views of dementia can delay diagnosis and physician's refer to using euphemistic language or passing responsibility for formal diagnosis to specialists to avoid this stigma Physicians recognised the need for education and support for family caregivers but felt limited in what they 	75%

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Reference	Setting	Aim	Sampling Criteria	Participants	Data Collection , data analysis	Key results	Mixed Methods Appraisal Tool Score
						could offer	

Table 3. Terms used in communicating a diagnosis from quantitative studies

Medical terms	Alzheimer's disease	GPs 14%	(Caruana-Pulpan and Scerri, 2014)
		PCPs 20%	(Jones et al., 2010)
		GPs 20%, Specialists 25%, Specialists 41% PWD, 82% family	(De Lepeleire et al., 2004)
		GPs 25% PWD, 87% Carer	(Tarek et al., 2009)
		GPs 37%	(Cantegreil-Kallen et al., 2005)
	Dementia	GPs 24%	(Downs et al., 2002)
		PCPs 25%	(De Lepeleire et al., 2004)
		GPs 34%	(Cody et al., 2002)
		GPs 37%	(Caruana-Pulpan and Scerri, 2014)
	Multi-infarct dementia	GPs 37%	(Downs et al., 2002)
PCPs 42%		(Cody et al., 2002)	
Vascular dementia	GPs 12%	(Downs et al., 2002)	
	PCPs 77%	(Cody et al., 2002)	
Euphemistic terms	Cognitive problems	GPs 8%	(Caruana-Pulpan and Scerri, 2014)
	Confusion	PCPs 63%	(Downs et al., 2002)
		GPs 51%	(Cody et al., 2002)
	Degenerative disease	Specialists 34% PWD, 21% family	(Tarek et al., 2009)
	Forgetfulness	GPs 15%	(De Lepeleire et al., 2004)
	Memory problems/ disease/impairment	GPs 26%	(Caruana-Pulpan and Scerri, 2014)
		PCPs 35%	(Downs et al., 2002)
GPs 36%		(De Lepeleire et al., 2004)	
GPs 93 %		(Cody et al., 2002)	
Slowing down due to ageing	Specialists 54% PWD, 17% family	(Tarek et al., 2009)	
	GPs 15%	(Caruana-Pulpan and Scerri, 2014)	

Table 4. Patient circumstances and other factors impacting on whether a diagnosis of dementia is communicated from quantitative studies

Beliefs favouring communicating diagnosis	Right to know	GP 2% PCP 46% Specialists 96%	(De Lepeleire et al., 2004) Cody, 2002 #14} (Tarek et al., 2009)
	Right thing to do	PCP 12%	(Cody et al., 2002)
	Handling personal affairs	GP 16%	(De Lepeleire et al., 2004)
	Promoting good doctor-patient relationship	GP 15%	(De Lepeleire et al., 2004)
	Know what to expect	PCP 11% GP 66%	(Cody et al., 2002) (Caruana-Pulpan and Scerri, 2014)
	Motivation to take drugs	GP 19%	(De Lepeleire et al., 2004)
Beliefs against communicating diagnosis	Lead to social stigma	GP 8%	(Caruana-Pulpan and Scerri, 2014)
	Destroying hope	GP 56% Specialists 60% Specialists 69%	(De Lepeleire et al., 2004) (Johnson et al., 2000) (Raicher et al., 2008)
	Lead to psychological distress	PCP 4%	(Cody et al., 2002)
		GP 16%	(Caruana-Pulpan and Scerri, 2014)
		GP 36%	(De Lepeleire et al., 2004)
Specialists 55%		(Raicher et al., 2008)	
Specialists 82%	(Tarek et al., 2009)		
Specialists 88%	(Johnson et al., 2000)		
Patient circumstances	Certainty of diagnosis	Specialists 49%	(Raicher et al., 2008)
		GP 54%	(De Lepeleire et al., 2004)
		GP 54%	(Vassilas and Donaldson, 1998)
		Specialist 68%	(Johnson et al., 2000)
	Patient said they don't want to be told	GP 34%	(De Lepeleire et al., 2004)
		Specialists 42%	(Raicher et al., 2008)
		Specialists 75%	(Johnson et al., 2000)
	Patient unable to understand	PCP 4%	(Cody et al., 2002)
Patient insight	GP 75%	(De Lepeleire et al., 2004)	
	Specialist 88%	(Johnson et al., 2000)	
Patient personality	Specialists 30%	(Johnson et al., 2000)	
	Specialists 51%	(Raicher et al., 2008)	
	GP 59%	(De Lepeleire et al., 2004)	
Family don't want patient to know	GP 39%	(Caruana-Pulpan and Scerri, 2014)	
	Specialist 38%	(Johnson et al., 2000)	
	GP 41%	(De Lepeleire et al., 2004)	

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		Specialists 67%	(Raicher et al., 2008)
Severity of dementia		GP 31%	(De Lepeleire et al., 2004)
		Specialists 59%	(Raicher et al., 2008)
		Specialist 75%	(Johnson et al., 2000)
Patient age		Specialists 25%	(Raicher et al., 2008)
		GP 28%	(De Lepeleire et al., 2004)
		Specialists 28%	(Johnson et al., 2000)
Co-morbidity		Specialists 34%	(Raicher et al., 2008)
		GP 38%	(De Lepeleire et al., 2004)
		Specialist 38%	(Johnson et al., 2000)
Financial situation		GP 10%	(De Lepeleire et al., 2004)
		Specialists 10%	(Johnson et al., 2000)
		Specialists 13%	(Raicher et al., 2008)

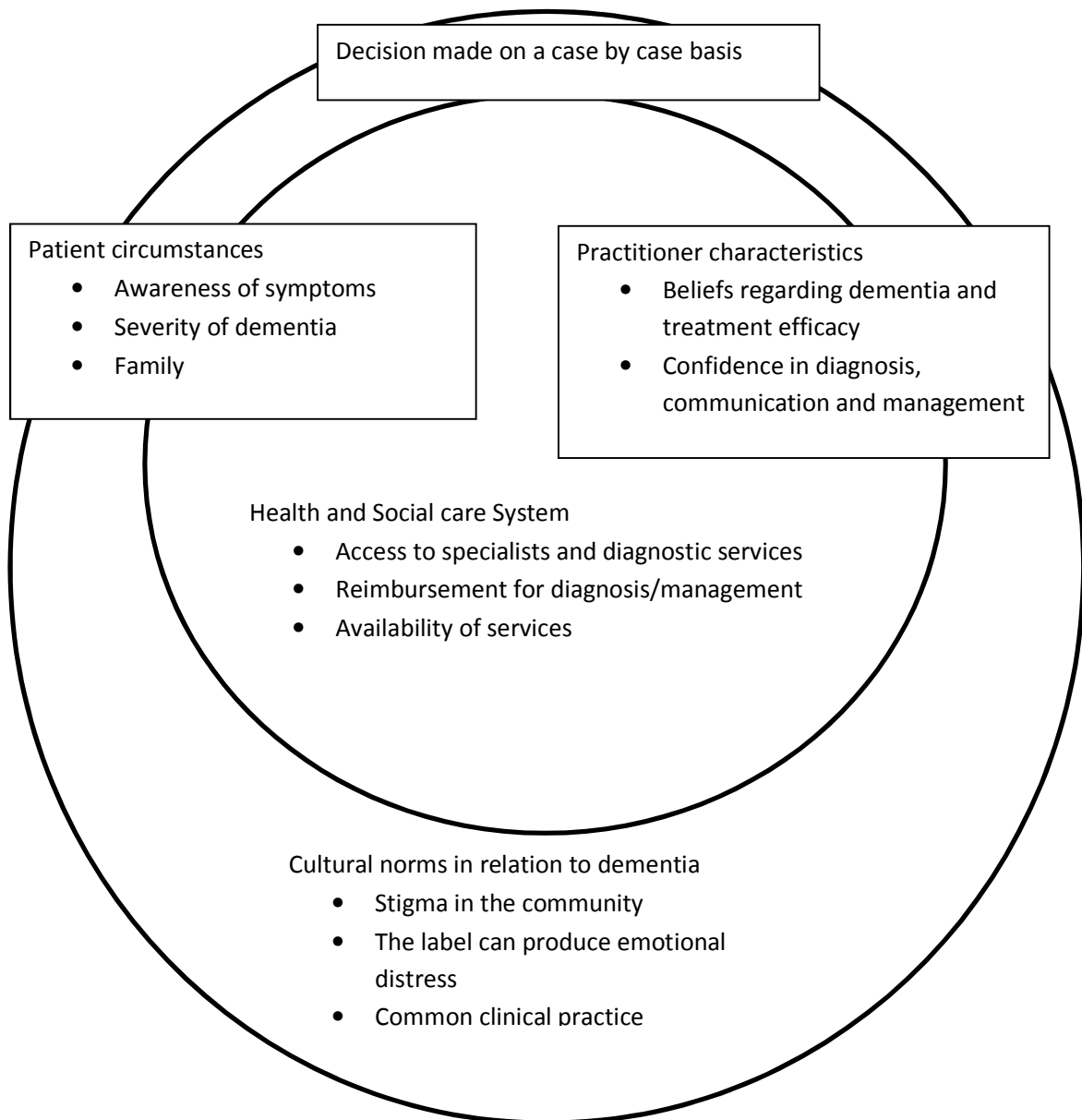
Table 5. Practitioner's beliefs and confidence regarding dementia diagnosis and treatment from quantitative studies

Benefits to diagnosis	Beneficial to receive a timely diagnosis	GPs 43%	(Milne et al., 2005)
		GPs 45%	(Milne et al., 2000)
		GPs 52%	(Renshaw et al., 2001)
		GP 85%	(Fox et al., 2014)
Benefits to diagnosis	Telling person with dementia usually more helpful than harmful	Hospital general practitioners 54%	(Pathak and Montgomery, 2015a)
		GPs 65%	(Turner et al., 2004)
		GP 70%	(Fox et al., 2014)
	Telling diagnosis and prognosis does more harm than good (rated from 1 to 6)	GPs mean 2.4 ± 1.3 Specialists mean 2.3 ± 1.2	(Kaduszkiewicz et al., 2008a, Kaduszkiewicz et al., 2008b)
Limited benefits to diagnosis	AD/Dementia is untreatable	GP 5%	(Fox et al., 2014)
	No point diagnosing dementia because support not available	GP 29%	(Fox et al., 2014)
	Early detection of dementia has no therapeutic consequences (rated from 1 to 6)	GPs mean 1.9 ± 1.3 Specialists mean 1.7 ± 1.2	(Kaduszkiewicz et al., 2008a, Kaduszkiewicz et al., 2008b)
	PWD can be a drain on resources with little positive outcome	Hospital general practitioners 39%	(Pathak and Montgomery, 2015a)
	Confident making diagnosis	PCP 34%	(Rubin et al., 1987)
Confidence in diagnosis and management		GP 52%	(Downs et al., 2000)
		Hospital general practitioners 67%	(Pathak and Montgomery, 2015a)
		GPs 73%	(Vassilas and Donaldson, 1998)
	Difficulty with early detection	GPs 39%	(Olafsdottir et al., 2001)
	Difficulty with early detection	PCPs 59% specialists 30%	(Jones et al., 2010, Martinez-Lage et al., 2010)
	Diagnostic capacity (rated 1-10)	GPs mean 6.2 ± 2.0	(Gaboreau et al., 2014)
	Not confident telling patient	GP 41%	(Downs et al., 2000)

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	Not confident telling family	GP 21%	(Downs et al., 2000)
	Confident in providing advice in managing dementia	Hospital general practitioners 46%	(Pathak and Montgomery, 2015a)
	Managing dementia is more often frustrating than rewarding	Hospital general practitioners 55% GPs 38%	(Pathak and Montgomery, 2015a) (Turner et al., 2004)
	Management of people with dementia moderate or very stressful	GPs 60%	(McIntosh et al., 1999)
	I would prefer to have nothing to do with the care for PWD (scored 1-6)	GPs mean 2.0 ± 1.2 Specialists mean 1.7 ± 1.3	(Kaduszkiewicz et al., 2008a, Kaduszkiewicz et al., 2008b)

Figure 4. Factors that relate to on a practitioner's decision to diagnose and communicate the diagnosis of dementia based on qualitative data



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