What is the role of the PN in the care of people living with dementia, or cognitive impairment, and their support person(s)?: A systematic review.

**CURRENT STATUS:** UNDER REVISION

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DOI:

10.21203/rs.2.20338/v1

**SUBJECT AREAS**

General Practice

**KEYWORDS**

Practice, Nurse, Primary Health, Care, Nurse, Dementia, Cognitive impairment
Abstract

Background: The potential value of expanding the Practice Nurse role to include the recognition and management of dementia has been acknowledged and Practice Nurses are well-positioned to provide comprehensive dementia information and support so that people living with dementia are better equipped to self-manage their health and live well with dementia. The purpose of this review was to systematically examine published Australian and international literature to identify the existing and potential roles of Practice Nurse’s involvement in the delivery of care to people living with dementia or cognitive impairment and their support person(s) and also describe the characteristics and effectiveness of nurse interventions in dementia models of care in general practice.

Methods: We systematically reviewed the evidence for roles and characteristics of the Practice Nurse in the delivery of dementia care. A comprehensive literature search identified relevant original research published in English between January 2000 and January 2019 and available in full text. Thirteen articles were included.

Results: Characteristics of roles, undertaken by nurses working in the general practice setting, which were potentially beneficial to people living with dementia and their support person were identified. These included increased patient accessibility to the Practice Nurse, early recognition and management of cognitive changes, care management and collaboration with the General Practitioner. Limitations of the provision of dementia care by Practice Nurses included a lack of definition of the role, inadequate dementia specific training, time constraints and poor communication with General Practitioners.

Conclusions Further research is required to define and evaluate the scope of practice and characteristics of the Practice Nurse role in dementia care provision. Embedding in usual general practice care an evidence-based model of care describing the role of the Practice Nurse in dementia care provision has the potential to increase early recognition of cognitive impairment and more appropriate primary care management of dementia. Systematic Review registration number PROSPERO 2018 CRD42018088191

Background
Australian and international literature [1, 2] reveals a significant gap in the delivery of dementia care in the general practice setting. In one study, 66% of participants (people with memory concerns) reported that they would like a memory test and 81% reported that they would speak with their General Practitioner (GP) if they thought they had dementia [3]. However, despite people’s intent to report their concerns with their GP, there is a significant gap in the delivery of dementia care in the general practice setting [1]. Barriers to the identification, diagnosis and management of dementia are multiple and complex, and in some cases include a perception by the GP that nothing can be done and that support options are lacking [4]. Dementia is the second leading cause of death in Australia and currently more than 400 000 Australians are living with dementia (ABS, 2016). This number is expected to increase three-fold by 2056 [5]. Around 83% of all males with dementia and 71% of females with dementia live in the community [5] with 50 percent of dementia cases remaining undiagnosed [6]. When combining these figures with the approximately 200 000 unpaid care-givers involved in supporting a person living with dementia [5] a significant number of people are likely to be attending general practices and not having their health and social care needs met. Exploring new ways to improve the identification and management of dementia in the primary care setting is needed.

Approximately two thirds of Australian general practices employ a nurse [7] and nurse-led clinics are known to maximise patient health outcomes in primary care [8, 9]. The Practice Nurse (PN) is a primary health care nurse employed in General Practice. As described by the Australian Primary Health Care Nurse Association (APNA) the role of the PN can include women’s health, men’s health, aged care, chronic disease management, immunisation, wound management, health promotion and population health. Given that co-morbidity in people living with dementia is high [8, 10] the PN is likely to have established a therapeutic relationship through routine primary care treatment, over-75 health checks and chronic disease management with people with cognitive decline [11].

The potential value of expanding the PN role to include the recognition and management of dementia has been acknowledged [12, 4]. However, there is limited research on the role of the PN in dementia care delivery in Australian or in international literature. A significant barrier to GP’s discussing
dementia with their patients is the perception that nothing can be done and that support options are lacking [4]. Developing a model of dementia care that incorporates a flexible clinical pathway to guide the PN, along with a compendium of resources that can be used to draw upon additional knowledge to assist in providing appropriate care for people with dementia, could help to overcome these barriers. The PN could offer the GP a means of providing immediate support to patients and their families, following a discussion about dementia that includes a conversation about their concerns and referral on to further supports as needed.

In summary, a PN model of dementia care has the potential to assist with the identification of cognition concerns and understanding of the impact of dementia on the health and well-being of an individual. Such a model is not only likely to lead to increased identification of dementia but also to more appropriate primary care treatment, chronic disease management, and, care planning for people with existing or emerging cognitive impairment or dementia and the people supporting them. To date there has been no systematic review of the evidence on the role of the PN in dementia care delivery.

Methods
This paper systematically reviews international and national peer-reviewed academic literature to answer the review questions:

1. What are the existing and potential roles performed by the PN in the care of people living with dementia or cognitive impairment and their informal caregivers in General Practice?

2. What are the characteristics of any existing nurse interventions that provide care to people living with dementia, or cognitive impairment, and their informal caregivers in the General Practice setting?

This systematic review was guided by the PRISMA-P Checklist [13] which comprises a 27-item
checklist for systematic reporting. The checklist includes items deemed essential for systematic review reporting [14].

**Eligibility criteria**

All research and other academic literature that described a role in care of a person with dementia and/or their caregiver performed by a nurse in a General Practice setting published between the dates 1 January 2000 and 1 January 2019 were eligible for inclusion. Studies were limited to those available in full text and published in English language.

**Information sources**

A search strategy was developed to identify published peer-reviewed studies describing the role of the PN in the care of people living with dementia, or cognitive impairment, and their informal caregivers in general practice.

Seven electronic databases (Cochrane Library, EMBASE, CINAHL (EBSCO), OVID MEDLINE (PubMed), Scopus, INFORMIT HEALTH and PsycINFO) and Google Scholar were searched.

A review of the included paper’s reference lists and citations was undertaken to identify any additional studies initially omitted from the primary search.

**Search strategy**

Original searches were carried out on the 24th February, 2018. Automatic search strategies for all included electronic databases were set up with weekly email alerts to identify eligible studies.
published from the date of the original search to 1st January 2019. Search terms used included:

1. Practice Nurse, Primary Health Care Nurse, Primary Care Nurse, General Practice Nurse, General Practice Nurse (MeSH Nurse)
2. Dementia, Cognitive impairment, Cognitive deficit, Alzheimer’s disease, Memory loss, Vascular dementia, Lewy body dementia, Frontotemporal dementia, Younger onset dementia (MeSH Dementia) Cognitive impairment, Cognitive deficit, Cognitive decline, Cognitive dysfunction (MeSH Cognitive dysfunction)

Example of a search query

Medline
1. (Practice Nurs* or Primary Health Care Nurs* or Primary Care Nurs* or General Practice Nurs* or GP Nurs*).af.
2. (Dementia, or Cognitive impairment or Cognitive dysfunction or cognitive deficit or cognitive decline or alzheimer* or memory impairment or memory loss).af.

**Study selection**

All records from searches were retrieved in Endnote reference management software, and transferred to Covidence, the on-line standard production platform for Cochrane Reviews (https://www.covidence.org/home). Using Covidence, all records were independently screened for eligibility using the identified inclusion criteria by two authors (CG and DG). Any discrepancies were resolved by a consensus meeting with the third author (DP).

The steps taken for paper selection included:

An initial screening for relevance using the titles of identified references. Papers considered to be irrelevant were removed from the selection process. A conservative approach was taken.
Abstracts of remaining titles were reviewed based on inclusion criteria. The abstracts were coded relevant/irrelevant/unsure. The irrelevant papers were discarded from the selection process. Full text papers were retrieved for abstracts categorised as relevant or unsure.

The full text papers were reviewed and those papers deemed relevant meeting the selection criteria were included in the systematic review.

**Data Collection processes**

Data extraction for all study types included: author, year, country; aim; research design; instruments; sample and size; intervention type; analysis methods and outcomes.

**Risk of bias in individual studies**

Two reviewers (CG, DG) independently assessed the risk of bias in included studies. Any disagreements between the reviewers were resolved by discussion, with involvement of a third reviewer (DP).

Each included study was assessed using a quality appraisal tool appropriate for the methodology used. Randomised Controlled Trial (RCT) studies were assessed for risk of bias using the Cochrane Risk of Bias Tool [15] in which bias was assessed as a judgement (high, low or unclear) in five domains: selection, performance, attrition, reporting and other. The CEBM Critical Appraisal tool [16] consists of 10 questions to assess the risk of bias in methodology, analysis and outcomes in cross-sectional studies with each question answered Yes, No or Can’t tell. The mixed methods data was appraised using the Mixed Methods Appraisal Tool (MMAT) Version 2018 [17]. The MMAT contains 21 questions for appraisal of the methodological quality of five categories: qualitative research, RCT, non-RCT, quantitative descriptive studies and mixed-method studies. Each criteria is assessed as Yes,
No or Can’t tell. Risk of bias in qualitative studies was appraised using a tool based on the Critical Appraisal Skills Programme (CASP) Qualitative checklist [18]. The CASP checklist asks; Are the results of the study valid?; what are the results?; and will the results help locally.

A summary of the quality appraisal for each study is presented in Tables 1, 2, 3 and 4 and any issues of potential bias for a given study are reported in the synthesis of the studies.

**Synthesis of results**

The data were synthesised to classify how the published academic literature addresses the research question and to identify and analyse key concepts. Data were heterogeneous and did not allow for meta-analysis.

A comparison of the studies and their findings was therefore conducted to synthesise the data into tables according to their methodological nature. Where the findings of a study have been published in more than one journal, the data have been grouped as the primary source together with the publication with the most detailed analysis. The other papers describing the same study were described as supplementary papers.

Data were extracted from the studies and tabulated under the headings: research aim; study design; instruments; sample characteristics; intervention type; analysis and outcomes. (Tables 5, 6, 7 and 8). This approach provided an analysis of the published academic literature and enabled the exploration of relationships within and between studies and a description of themes across the included studies.

**Results**
The search strategy identified 1875 references (Figure 1). After removal of duplicates 1799 abstracts were examined for relevance and 68 full text references were obtained for full text screening. Hand-searching of references lists of included articles yielded an additional three articles. In total 71
articles were assessed for eligibility, of which 13 articles were selected for data extraction and analysis.

Fifty-eight studies assessed for eligibility were excluded. Eighteen were grey literature, 17 did not include the primary health care nurse, six were not available in full text, seven papers were removed as they were multiple publications reporting on the same intervention, five were published outside of the time-frame for inclusion, three were duplicate studies [19-21] and two studies [22,23] were excluded as the outcomes had not been published. Bryans et al., [22] did not publish the outcomes of a survey study on primary health care nurses and dementia care due to significant loss to follow-up. For similar reasons, Perry et al., [23] did not publish the outcomes of the dementia training programme on diagnostic assessment and management of dementia by primary care nurses.

**Study characteristics**

Of the 13 included studies, three were RCTs, three utilised survey questionnaires, four were mixed-method studies with one of these a Rand-Delphi study, and three were qualitative studies using interviews.

The studies were conducted in the Netherlands (n=1), Germany (n=1), United States of America (n=1), The United Kingdom (n=5), Australia (n=4) and one was conducted across the Netherlands and the United Kingdom (n=1).

All the studies were published between 2000 and 2019.

Four studies [21,24-26] evaluated dementia care management in primary health care. Exploring dementia care knowledge and attitudes of primary health care practitioners was the focus of three studies [11,12,3]. Two studies [27,28] explored participant experiences of dementia care delivery in
primary health care and one study [29] explored service use and reported unmet needs of people with dementia and support person(s). Investigating the implications of early recognition of dementia for the roles of the primary health care team was the focus of one study [30] The authors of one study [31] developed quality indicators for dementia care in primary health care settings and one study investigated the value and useability of an online dementia management tool for health professionals [32]. The study characteristics are described in Tables 5, 6, 7 and 8.

**Randomised Controlled Trials**

Three studies utilised an RCT [21,25,26] to investigate the impact of collaborative care on quality of life for people with dementia and their caregivers. The study by Van den Dungen et al., [25] also included an evaluation of family practitioner training on diagnosis of mild cognitive impairment.

In all three models of care the nurse was the care manager who worked in collaboration with the primary care doctor. All care management models followed a structured assessment and care planning protocol. Care management ranged in duration from six [26] to twelve months [21, 25]. In two studies [25,26] the care managers were registered nurses, with Van den Dungen et al., [25] specifying the nurse as a primary care nurse who acted as the study nurse. In the third study [21] the care manager was a geriatric nurse practitioner. All the nurses received dementia specific training and were integrated into the primary care team with only one care manager providing the dementia care management within the patients’ home [26].

Callahan et al., [21] and Thyrian et al., [26] reported a significant decrease in behavioural and psychological symptoms of dementia and caregiver stress with dementia care management, however, Thyrian et al., [26] reported there was no significant improvement in quality of life overall. Despite reporting that dementia care management had no impact on quality of life measures for patients or their care-givers, Van den Dungen et al.,[25] do recommend that collaborative care with nurses in
primary care deserves further exploration. Authors of all three studies reported limitations in generalisability, however, Callahan et al., [21] and Thyrian et al., [26] recommend dementia care management be provided by specifically trained nurses as an effective collaborative care model and implementation in routine care could be beneficial for people living with dementia and their care-givers.

Callahan et al., [21] tested the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer’s disease at primary care practices within two university affiliated health care systems from January 2002- August 2004 in the US. This model of care is part of the Prevent Study [20]. The study was designed to apply the shared elements of current treatment guidelines for patients with Alzheimer’s disease [21]. The essential components of the model of care were a comprehensive screening and diagnosis protocol [33], a multi-disciplinary team approach to care coordinated by a geriatric nurse practitioner and a proactive longitudinal tracking system [20]. The primary outcome measurement was the identification and treatment of behavioural and psychological symptoms of dementia, with an emphasis on non-pharmacological management.

Intervention patients received care management by an interdisciplinary team led by the nurse working with the patient’s family caregiver and integrated within primary care [20,34]. There was one nurse in each of the two study primary care practices, with each site including multiple clinics. This nurse was a geriatric nurse practitioner who had received specific training in communicating the diagnosis of Alzheimer’s disease to patients and families. In addition to training, the nurse participated in weekly support meeting with a geriatrician, geriatric psychiatrist and a psychologist who reviewed the care provided. Caregivers and patients were seen by the nurse in the primary care clinic fortnightly, then monthly for one year. At each contact caregivers completed the Memory and Behaviour Problems Checklist which activated a specific behavioural intervention protocol [20]. The nurse managed non pharmacological interventions independently and if the intervention was unsuccessful then collaborated with GP to institute drug therapy. Advice on communication skills;
strategies for managing support person(s) stress; legal and financial advice; physical activity guidelines and the Alzheimer’s Association Caregiver Guide was the minimum intervention that all treatment group caregivers received included [20]. Caregivers were also invited to participate in a monthly support group with a concurrent exercise program for the person with dementia [19].

The intervention group had fewer behavioural problems and reduced support person(s) stress, but there was no significant impact on depression or function. There was no evidence that the intervention improves or worsens cognition, activities of daily living or the rate of nursing home placement.

The results of this study indicate that this type of model of care can be implemented in primary care, particularly with the involvement of geriatric advanced practice nurses, who can effectively manage the complex nature of Alzheimer’s disease. Callahan et al., [21] report that the effectiveness of the intervention depended on the key role played by the nurse. The model of care was acceptable to patients and primary care physicians [19] improving primary care efficiency. Factors important to nurses’ success included establishing good relations with primary care physician, effective communication with the primary care physician and familiarity with primary care settings [20]. The intervention strength is credited to its comprehensive and integrated approach in line with effective chronic disease management models [21]. This model of care is potentially more health care intensive as the patients receiving care management had higher cumulative doctor or nurse visits compared with usual care, however these costs may be off-set by a reduction in pharmacological management of behavioural and psychological symptoms of dementia [21].

Callahan et al., [21] describe the main limitation of the study as the inability to identify which of the subcomponents of the intervention were most effective in achieving the outcomes. The strength of the intervention was its comprehensive and integrated approach. Other identified limitations included limited generalisability as the sample size may not have provided sufficient power to detect minor
changes in cognition or nursing home placement.

Van den Dungen et al., [25] conducted a 2 stage cluster RCT assessing the outcomes of education, case-finding and subsequent care on diagnosis of mild cognitive impairment (MCI) and the mental health effects of case finding and subsequent care [34].

The intervention included five hours of face-to-face family practitioner training to increase knowledge to diagnose dementia, a practice guideline and a trained PN to facilitate the diagnostic process and collaborative care. There were two study nurses covering seven participating practices. Collaborative care included the PN prioritising problems and preparing a care plan using the results of the administration of the Residential Assessment Instrument [36] and in collaboration with the individual with dementia or MCI, the caregiver and the GP.

The study outcomes were a non-significant increase in MCI and dementia diagnoses resulting from a combined educational, case finding and care intervention. Collaborative care did not seem to have impact on mental health and quality of life for study participants. The family practitioners and PNs described case-finding and the provision of collaborative care as a positive experience, however the PN did describe the process of inviting people for an assessment as time-consuming.

Limitations to the study included low response rates limiting the external validity of the study. The rates of MCI or dementia were lower than expected. The reasons for this may have included a type 2 error with a low sensitivity of the cognitive tests performed by PN. In addition, there was sub-optimal implementation of the intervention with the family practitioner not always performing further diagnostic assessments on all persons referred by the PN. The potential impact of the intervention on rate of new diagnosis may have been mitigated by these factors.

Thyrian et al., [26] tested the effectiveness of dementia care management (DCM) in the treatment
and care of people with dementia living at home and on caregiver burden [37]. DCM is a collaborative care model that uses a computer-assisted program to determine a personalised array of intervention modules and subsequent success monitoring that will provide optimal treatment and care for people with dementia and support caregivers. A RCT involving 634 people with dementia was conducted with six nurses who had completed a dementia care-specific qualification to provide the DCM intervention [38]. The intervention was provided for 6 months in the homes of the people with dementia. This study found that DCM was a safe intervention significantly decreasing behavioural and psychological symptoms of dementia and care giver burden. People with dementia with DCM had an increased chance of receiving anti-dementia drug treatment. DCM significantly increased QOL for patients not living alone but did not increase QOL overall. There was no effect on the potential administration of inappropriate medication.

It was recommended that DCM provided by trained nurses was an effective collaborative care model improving patient and caregiver outcomes and should be incorporated into routine primary health care. However, the DCM qualification piloted in Dreier et al., [38] is time intensive with 35 modules over 18 months, which would not be easily accessible for all primary care nurses.

Thyrian et al., [26] describe limitations of the study including potential selection bias as screening and recruitment were part of routine care. The intervention and control groups had an uneven number of participants; the GPs in the control group had fewer patients. In addition, the GPs may have become aware of their assignment to the control or intervention group. The study was embedded into routine care resulting in high external validity.

**Survey Questionnaire studies**

Three studies reported survey results [11,12,29]. Manthorpe et al., [12] and Trickey et al., [11] investigated dementia knowledge and attitudes of primary health care nurses (CN), health visitors, community mental health care nurses (CMHN) and PNs in the provision of care for people living with dementia. The third study [29] explored service use and unmet needs of people with dementia.
recruited a decade apart.

Manthorpe et al., [12] reported all groups of primary health care nurses had similar knowledge related to the early signs and symptoms of dementia. However, PNs were less confident in providing advice and support than community mental health care nurses. In the study undertaken by Trickey et al., [11], PNs completing the Over-75 year health check were less likely than other nurse groups to take any action, other than to refer to the GP, when presented with a person living with dementia and their support person.

Gilbert et al., [29] reported that support person(s) were increasingly contacting a PN for support with less evident use of CN, health visitors and CMHN. This may in part be attributed to greater access to a PN and the changing nature of the PN role with an increased focus on chronic disease management. Support person(s) reported that they were still not getting the advice and support they needed.

Authors of all three studies identified a need to improve PN knowledge of dementia and its management. In the study by Trickey et al., [11] participants reported guidelines would be helpful to address gaps in knowledge and to standardise practice.

The survey outcomes and study limitations are described in detail below.

Manthorpe et al., [12] administered a questionnaire to 268 nurses; comprising 79 CMHNS, 153 CNs and 36 PNs, to explore whether there had different perspectives on early diagnosis of dementia and to consider the effects of any variation. These questionnaires were completed by nurses who attended one-day workshops offered on 24 occasions in 21 settings across the UK over a three month period. The workshops were open to all health practitioners who worked in the community setting and were part of a training program on early diagnosis of dementia [39].
All of the nurse groups were in regular contact with people with dementia and were able to respond to early signs of dementia and identify potential sources of support. However, both PNs and CNs felt less confident in the provision of dementia care and service co-ordination than community mental health care nurses. Once a diagnosis had been given approximately half of the PN respondents reported that they found it challenging to provide advice and support about behavioural or psychological problems. About one third of PNs found providing information about support services and obtaining support services “considerably difficult” with slightly more reporting “considerable difficulty” in the co-ordination of services. Dementia support in the community was seen by all nurse groups as a specialist function with the key worker role best fulfilled by community mental health care nurses. A limitation in drawing generalizable conclusions from this study was that the nurse participants volunteered to attend a 1-day training course on dementia in their own time. Therefore, the sample group was likely a group of interested and perhaps atypical practitioners. However, when considering the role of the PN in the provision of dementia care the authors conclude that despite PNs being in contact with the population likely to benefit from early recognition of dementia, work is needed to increase PN confidence, knowledge and skills in recognising dementia and supporting people undergoing referral or assessment.

Trickey et al., [11] utilised a postal questionnaire survey that was completed by 127 primary care nurses in the UK (a response rate of 65%) of which 71% were practice based nurses. The study aimed to examine the knowledge, attitudes and inter-professional working practices among nurses who undertake the Over-75 Check towards assessing and managing patients with symptoms of dementia. The survey also assessed the level of support for a clinical practice guideline.

The outcomes of the study revealed there was little evidence of a systematic approach within practices. Twenty-five percent of survey respondents indicated they would take no action other than to refer to a GP in response to a case vignette describing a consultation with an older couple; the wife showing signs of dementia and the husband anxious about the future. Of the remaining participants,
there was a mixed response to the action they would take, with little evidence of holistic assessment and care. Just under one third reported they would make an informal or formal assessment of cognition, 5% would explore the husband’s mood and 1% would look at specific support needs for the husband. The extent of action nurses indicated they would take was dependant on their skills and perception of autonomy, with most intended action reported by highly trained nurses with more confidence and perceived autonomy. Trickey et al., [11] concluded that many professionals undertaking the Over-75 health check are not sufficiently trained to assess patients with potentially early signs of cognitive impairment. The majority of respondents recognised the need to standardise care and the need for early intervention and indicated that guidelines would be helpful in their practice to address gaps in knowledge. This was a small survey conducted in a limited geographical area which restricts drawing generalizable conclusions. Additionally, using a vignette may more correctly be exploring current practice rather than knowledge and attitudes. However, given the prevalence of PNs undertaking the Over-75 Check in General Practice it is reasonable to conclude that education to support recognition of cognitive impairment and the provision of consistent and adequate care for people with dementia is warranted.

Gilbert et al., [29] report the results of a UK study comparing service use and unmet needs by people with dementia and their support person(s) in two samples a decade apart using the same survey instrument. The participants in this study were recruited in two earlier RCTs [40,41] testing the effectiveness of the EVIDEM dementia educational intervention [41] and support person(s) accounts of their encounters with family practice [40].

Recruitment was part of an educational intervention study and those taking part in such trials are not representative of the wider community of people with dementia and their caregivers. Despite this limitation the two samples were largely similar in demographics. There were statistically significant differences in service use and unmet needs between the two samples, with a reduction in unmet need in the second sample. However, managing physical and verbal aggression remained a significant
challenge. Gilbert et al., [29] report this reduction may be related to changes in service use and national policy promoting earlier recognition, improved access to treatment, specialist services and social supports and better identification and recognition of support person(s). In the second sample, the role of PNs was more evident, especially for non-spouse support person(s), and the use of CNs, CMHNs and home visitors was less apparent. It is not known if these contacts were to review dementia or were encounters for management of co-morbidities.

Despite the outcome that PNs have a more evident role in caring for people living with dementia, Gilbert et al., [29] do not elaborate on what that role may look like. The authors conclude that better understanding of the increasing role of the PN may help primary care health professionals to reduce the unmet needs among support person(s) for people with dementia.

**Mixed methods**

Four studies reported mixed-methods research results [3,24,31,32].

Perry et al., [31] used a RAND modified Delphi method to construct a set of quality indicators for dementia diagnosis and management in primary care in the Netherlands. PNs were involved in the selection and validation process of the quality indicators. Of the final 23 quality indicators, two explicitly describe collaboration between the GP and the PN, an area in which the authors suggest improvement is highly recommended. A further three quality indicators emphasise the importance of developing and reviewing individualised care plans. This is commonly a PN role that is established and accepted in primary care settings. Millard et al., [3] explored dementia literacy in a general practice setting. In this study two-thirds of the PNs reported a lack of dementia training. Despite this self-perceived lack of training, three-quarters of the PNs reported that the primary care doctor or nurse was the appropriate person to discuss dementia with patients. Ollerenshaw et al., [32] suggest that PNs may find an on-line dementia management support tool useful. Iliffe et al., [24] adapted a US
model of primary care based case management (PREVENT) for people with dementia and tested its implementation in UK general practice. Despite case managers, patients and support person(s) reporting a positive experience and perceiving benefits of case management, the study outcomes suggested that case management does not fit easily into practice routines and that it was not substantially beneficial for patients and support person(s).

The outcomes and limitations for each of the studies outlined above are described in more detail below.

Ollerenshaw et al., [32] explored primary health care practitioner awareness and use of an online Dementia Pathways Tool [42] with surveys and Google Analytics in rural and regional western Victoria. Fifty percent of the survey respondents were PNs who reported finding the Dementia Pathways Tool useful in complementing their knowledge about dementia. This finding may suggest that PNs are interested in dementia and are seeking further information to support their practice. However, given the low survey response rate (13%) and the small sample size (n=21) it could also be concluded that PNs were not interested in, or see as relevant to their practice, the provision of dementia care. Although Google Analytics show consistent access and use of the Dementia Pathways Tool there is insufficient detail to reveal the type of user or information accessed.

Using a mixed-methodology that included questionnaires, an RCT, and computerised medical records data from 22 practices in Australia and 3 in the UK, Millard et al., [3] measured GP, PN and patient dementia related health literacy. The questionnaire study involved PNs and explored the source and adequacy of dementia knowledge. Twenty five Australian PNs and 1 English PN completed a one-page questionnaire about memory problems, dementia and its risk factors.

Results revealed that despite slightly over one third of PNs reporting that they had received dementia training, two thirds of PNs rated their dementia knowledge as inadequate. Over two thirds of patients
in the waiting rooms of the 25 practices wanted to learn more about reducing the risk of dementia, with only 15% having heard about dementia from a doctor. Approximately two thirds of PNs reported that a doctor or nurse was the appropriate person to discuss dementia with patients.

A limitation of this study was a convenience sampling strategy was used to recruit PNs. The results are therefore not representative of the health literacy of the PNs in the 22 practices in Australia or the three practices in the UK.

Iliffe et al., [24] adapted a successful primary care based care management model for people with dementia from the US (the PREVENT model) and used mixed- methodology case studies to test its acceptability and feasibility in General Practice in the UK. The translation and cultural adaptation of the PREVENT model and its testing was called the CARE-DEM study.

The CARE-DEM intervention consisted of training and mentoring based on an educational needs assessment and a learning manual that could be shared between case managers and patient-carer dyads. The training and mentoring was provided by an Admiral Nurse, a dementia care specialist CN.

The CARE-DEM intervention was tested in four general practices. PNs undertook the case manager role, with one nurse in each of two practices and one social worker who undertook the case manager role across two practices. Eligible participants were people living with dementia who had a support person, were not receiving care co-ordination from specialist services and were living in the community.

The authors reported on recruitment of dyads to participate in study, number of dyad and case manager contacts, type of needs identified, dyad interviews and interviews with NHS and social care professionals and the case managers.
Feedback from the dyads and National Health Service (NHS) and social care professionals was generally positive of case management. While all case managers perceived the benefits of case management as continuity of care and flexibility in meeting needs, the PN case managers reported that there were few concrete benefits to participants. All the case managers reported time constraints as an obstacle to working with their client group however the most successful case manager was a PN. This PN who had dementia care experience had only half a day available and carried a larger case manager load compared with the social worker who worked full-time across two practices.

Despite case management offering potential benefits, this study suggested that case management does not fit into practice routines easily and that case management was not significantly beneficial to patients or caregivers. The findings of this study are consistent with the view that case managers need a recognised defined role, comprehensive clinical skills, protected time and access to multidisciplinary expertise [24].

The small scale of the study means that conclusions drawn from it must be tentative. The limitations of this study included less than expected dyad recruitment for all practices. The time constraints for the case management role of the PNs may have meant there was insufficient time to show the potential of case management. Unmet needs discrepancies between case managers and researchers with the researchers identifying more unmet needs may have impacted on the experience of the dyads.

Perry et al., [31] constructed a set of quality indicators for dementia diagnosis and management in a primary care setting used a RAND modified Delphi method (postal survey, stakeholders’ consensus meeting, scientific expert consensus meeting, and demonstration). Along with GPs and informal support person(s), 21 PNs participated in the postal survey and two PNs participated in the stakeholders’ consensus meeting. Of the final set of 23 quality indicators several indicators explicitly describe collaboration between GPs and PNs, an area in which improvement is highly recommended.
One quality indicator specified that the GP be the first point of contact or delegate this task to the PN. Another quality indicator specified that GPs and PNs use the same medical record. Quality indicators are included on developing individualised care plans for each person and support person (after formal diagnosis made), with reviews every three months. However, this task was not explicitly assigned to either the GP or PN. This study showed that a PN’s positive attitude towards dementia care and collaboration was positively associated with adherence rates.

The incompleteness of the GP electronic medical record limited a quantitative assessment of feasibility of measurement and may have limited validity of adherence rates. However, in the postal survey most outcome indicators showed acceptable feasibility of measurement. Adherence rates to the quality indicators in this study were similar to those found in other studies measuring quality in primary dementia care. This suggests validity of the findings.

**Qualitative studies**

All three qualitative studies [27,28,30] used interviews to explore experiences of primary health care practitioners, patients and support person(s), of dementia care. Dodd et al., [27] used semi-structured face-to-face interviews to contrast study participants’ experiences of a new primary care led dementia service with existing secondary care based memory services in Bristol, UK. Dodd et al., [28] used a semi-structured face-to-face interview to investigate participant’s experiences of a new primary care led dementia service in South Gloustershire, UK. In both these studies [27,28] the nurses were seconded from secondary care dementia services, with each nurse working with a group of primary health care clinics. Patients and support person(s) reported primary care led services to be positive and there was uniform praise for the work by the memory nurse. GPs reported they valued the advisory role provided by the memory nurse. Manthorpe et al., [30] explored implications of the early recognition of dementia for inter-professional working using focus group interviews. In this study the PN was identified as the practitioner most appropriate to take on screening for dementia
and monitoring, however community mental health care nurses were considered to have the skills and capacity to take on long-term and complex cases.

Dodd et al., [27] used a qualitative participatory study to contrast patient, family member and health professional experience of primary and secondary (usual) care led memory services. Data were collected through peer led interviews. Eleven of the 53 General Practices in Bristol, UK, offered primary care led dementia services. Three memory nurses from the secondary care memory service were seconded to work with the 11 pilot practices. A referral from the GP to the memory nurse was used to trigger a home visit for the purpose of providing advice to the GP on assessment and management. GPs in the participating practices attended a three hour training programme on identifying, assessing and diagnosing dementia. This programme was delivered by the GP lead for dementia and the memory clinic service manager. In the model of a primary care led dementia pathway [28] GPs no longer automatically referred all patients with suspected memory problems to secondary care for assessment. GPs were expected to take the lead in assessing, making a diagnosis and providing treatment for patients suspected of having a dementia and, if possible, a diagnosis was made in primary care. When diagnosis was unclear the GP sought advice from the memory nurses seconded to primary care. A referral to a memory clinic was made if it was a complex diagnosis.

GPs reported they valued working with the memory nurse, however the memory nurses found liaising with GPs to be cumbersome and time consuming. All participants praised the work of memory nurses in both primary and secondary care settings.

Study limitations included: a low participation rate from those patients (n=14) and support person(s) (n=15) who were invited to take part; the potential to ‘hand-pick’ participants with secondary care Memory Clinics assisting with recruitment; peer researchers lacking experience in conducting research interviews and the study team’s inability to recruit a person living with dementia to the peer panel which developed the interview topic guide. The differences in secondary care models across
the country also limits the generalisability of the study’s findings to other areas.

Dodd et al., [28] investigated a primary-care led dementia service piloted in South Gloustershire, UK, during 2012 with 23 general practices participating. Unlike Dodd et al., [27] this study did not compare experiences of secondary care memory clinics. The aim of this study was to investigate how the South Gloustershire primary care memory service was experienced and understood by all those involved in the new process of assessment, diagnosis and treatment of dementia within a primary care service developed in the previous study by Dodd et al., [27]. The memory nurses were from secondary care dementia services, located centrally and provided expert consultancy to GPs around dementia medications. All the service users who were interviewed for this study had only been seen by their GP and not by memory nurses working in either primary or secondary care memory services.

The interviews revealed four main themes related to the relocation of part of the memory service from secondary care to primary care: ‘the journey’; ‘what next’; ‘the benefits and limits of primary care’; and, ‘are GPs getting it right’. Two consistently expressed concerns by all groups of participants were: lack of post-diagnostic co-ordination and GP-led or multidisciplinary assessment. The process of assessment and diagnosis was described by the GPs and memory nurses as a collaborative or multi-disciplinary exercise, but with clear boundaries between roles, with the nurse carrying out the assessment and the doctor making the final diagnosis.

Training and education was repeatedly identified as a means to develop collaborative, consistent approaches to dementia care. The memory nurses described how informal learning with experience and talking with their colleagues was particularly important in enhancing competence.

The study did not aim to be generalizable, but to generate ideas for further research. Limitations included the small sample size (n=7) and the use of peer interviewers.
Manthorpe et al., [30] conducted a focus group study with the same sample group attending a series of 24 multidisciplinary dementia workshops over 21 cities across UK over a three month period as reported in Manthorpe et al., [12] and Illiffe et al., [24]. Participants in the wider study included 247 GPs, 146 PNs, 79 CMHNs and others working in a range of hospital, residential and community settings. Four focus groups were conducted in each workshop. The multi-disciplinary focus groups comprised 20 participants which included PNs. Each group worked on a series of questions related to their work and to the design of dementia care services relevant to early recognition of and response to dementia.

Four categories of paired themes were identified; opportunistic screening versus population screening, referral and responsibility, key working and team working, and generalist versus specialist roles. Collaborative working in dementia care, particularly around early recognition, was seen as essential, with the PN identified as the practitioner most appropriate to take on routine screening for dementia in primary care. There was a contradiction between the perception that recognising dementia could be in the remit of all professionals, and the clear delegation of assessment to nurses. A perception that screening is a core skill that can be assimilated and incorporated into everyday practice by any nurse, although not necessarily by GPs, reflected the unresolved tension between opportunistic identification (which all could do) and a more systematic approach to screening, where nurses are seen by doctors as the most appropriate professional. A common theme was the need for education and training for screening. However that routine screening for dementia is controversial and not recommended due to the high rate of false positives [43]. There were concerns about the time required to provide more comprehensive dementia care in primary health care. Communication between professionals, increased requests for screening and assessment, the pressure of earlier reviews from those who enter the dementia systems at ever earlier stages and the higher expectations from older people and their families were seen to be costly and time-consuming.

The study outcomes are limited in generalisability because the sample was likely a group of
interested and perhaps atypical practitioners who volunteered to attend a one day training course on dementia in their own time.

Risk of bias

The methodological quality varied across the studies (Tables 1, 2, 3 and 4). The qualitative and all but one of the mixed methods studies rated high according to the quality appraisal criteria. Two of the three RCT studies lacked allocation concealment, blinding and presented incomplete outcome data which compromised their quality. The survey studies were of mixed quality with two of the three studies introducing selection bias; no sample size was based on consideration of statistical power and all survey study outcomes were unable to be applied to other primary care settings.

Discussion

This systematic review of the literature on the current and potential role of the PN in the delivery of care to people living with dementia or cognitive impairment and their support person(s) included 13 studies which were evaluated in this review.

There has been no previous systematic reviews of the role or potential role for the PN in the delivery of care to people living with dementia or cognitive impairment and their support person(s). The results from this review are therefore novel and should be used to inform the role of the PN in the provision of dementia care and also future research on this topic.

The results from our extensive review of the role PNs in the delivery of care to people living with dementia or cognitive impairment and their support person(s) provides level 1 evidence [44] in regard to evaluations of roles and characteristics of successful models of support for people living with dementia or cognitive impairment and their support person(s) in the general practice setting nationally and internationally.

The only clearly defined role that was examined was that of the primary care based nurse as a care manager [21, 24-26]. There were mixed findings regarding the effectiveness of the nurse-led case management model of care in improving quality of life measures for people living with dementia and
their support person(s). However, no studies dismissed the potential of this model, with further research recommended. Callahan et al., [21] was assessed as the highest quality RCT study. The authors reported that a case management model of care can be implemented in primary care and that the effectiveness of the intervention depended on the key role of the nurse. All the nurses in these care management studies were registered nurses with dementia specific training, however in the Callahan et al., [21] study the case manager was a geriatric nurse practitioner. All health practitioners in the care manager studies described the experience as positive and perceived there to be benefits to the patient. Nurses did describe the role as time consuming and liaising with the primary care medical practitioner as cumbersome. However, the care manager role was considered resource intensive, which could prove a challenge in its integration with practice routines that often operate, with limited time for consultations and budgetary constraints. The case management model described in Callahan et al., [21] was particularly resource intensive with one year of case management, weekly mentoring for the case manager, weekly then monthly patient contacts, and monthly care-giver support groups with concurrent exercise groups for the person living with dementia.

The other studies [3, 11, 12, 27–32] explored characteristics of the role of the primary care based nurse in the care of people living with dementia and the support person. These studies were of variable quality but consistent in their outcomes. The PN was described as having an increasing profile in primary health care and being more accessible to patients, partly as a result of their changing role to include chronic disease management. There was recognition of the primary care nurse as the appropriate professional to take on the role of screening for cognitive impairment and monitoring, with the medical practitioner being responsible for diagnosis. The PN is usually responsible for the Over 75 health check which is currently underutilised and provides an opportunity to identify people with cognitive impairment. A common issue in the studies was the poor recording of diagnosis or outcome of cognitive testing in electronic medical records. Several studies identified that post-diagnostic support and carer support were lacking in current dementia care provision in primary health care. Patients with memory concerns reported that they would welcome the opportunity to
discuss dementia risk reduction with the GP however the GP was not meeting this need [3]. This responsibility was reported as potentially within the scope of the primary care nurse role [3]. Developing good working relationships with the medical practitioner, familiarity with the primary care setting, perception of autonomy, dementia specific education and the embedding dementia care provision in primary health care were seen as essential to the success of the primary care nurse in dementia care provision. A consistent finding across the studies was that primary care nurses reported a lack of confidence in dementia care provision and the rating of their knowledge and skills as inadequate. This is despite the perception that nurses include themselves as an appropriate professional to discuss dementia with a patient. The need for education and training was stressed in all studies as necessary for successful dementia care provision. The use of guidelines was perceived as valuable by nurses to improve knowledge and standardise practice. Nurses in the care management models used detailed standardised protocols for dementia care provision. The heterogeneity of studies’ purpose, design and outcomes measures make it difficult to synthesise the findings and draw conclusions.

Implications for practice and research

There is justification for the involvement of the PN in the recognition and care of people living with dementia and their support person(s). However, there is little evidence on the scope of practice and framework of a primary care nurse model of dementia care provision. The different studies examined different aspects of the PN’s role in relation to dementia. These roles included care management, identification and/or management of behavioural, psychological and behavioural symptoms of dementia. Some nurses were seconded from secondary care memory clinics, some were registered nurses working in general practice and one was a geriatric nurse practitioner. Dementia training for the nurses also greatly varied across studies. In the studies the nurse had received specific training from several hours to months and the types of training differed in breadth and intensity.

More high quality studies are required to establish the scope of practice, effectiveness, cost implications and the applicability of the PN role in the care of people living with dementia, or cognitive impairment, and their support person(s) in general practice.
Strengths and limitations
This is the first systematic review to investigate the role of the PN in the care of people living with dementia, or cognitive impairment, and their support person(s) in general practice. An explicit, systematic methodology was followed to review the published peer-reviewed literature relevant to the topic. National and international literature was reviewed and the studies utilised a variety of methodologies including qualitative, quantitative and mixed methods. It was not possible to conduct a meta-analysis due to the heterogeneous nature of the interventions. The studies included in this review were published in English only and grey or white literature was not included. Some studies may not have been identified by the search terms used in each database.

Conclusions
The aim of this systematic review was to investigate the role of the PN in the care of people living with dementia, or cognitive impairment, and their support person(s) in general practice. The potential value of the PN in the recognition and management of dementia has been acknowledged. However, the findings of this review revealed that there is limited evidence on the role of the PN in dementia care provision. The strength of this review is the identification of benefits of roles fulfilled by nurses in the general practice setting for people living with dementia and their support person(s). These included increased patient accessibility to the PN, early recognition and management of cognitive changes, care management and collaboration with the GP. Limitations of the provision of dementia care by the PN included a lack of definition of the role, inadequate dementia specific training, time constraints and poor communication with GPs.

A model of dementia care provision with mechanisms to support the practice nurse role and the embedding of it in usual general practice care has the potential to increase early recognition of cognitive impairment and more appropriate primary care management of dementia.

Abbreviations
APNA Australian Primary Health Nurse Association
CMHN Community Mental Health Nurse
CN Community nurse
DCM Dementia Care Management
FP Family Practitioner
GP General Practitioner
MMSE Mini Mental State Examination
NHS National Health Service
QOL Quality of life
RCT Randomised Controlled Trial
Declarations
Ethics approval and consent to participate
Not applicable
Consent for publication
Not applicable
Availability of data and materials
Not applicable
Competing interests
The authors declared no conflicts of interest.
Funding
This research received no funding.
Author contributions
CG, DG and DP developed the review question, designed the review and developed the search strategy. CG and DG conducted the selection, undertook the data extraction and conducted the quality assessment. DP helped resolve any discrepancies in the quality assessment. CG and DG wrote the manuscript and DP provided critical commentary on initial versions of the manuscript. All authors have read and approved the final submitted manuscript.
Acknowledgements
This research contributes to a larger program of work being conducted by the Australian Community of Practice in Research in Dementia (ACcORD), which is funded by a Dementia Research Team Grant from the National Health and Medical Research Council. Caroline Gibson is supported by a University of Newcastle Postgraduate Research Scholarship from the Faculty of Health and Medicine.

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Tables

**Table 1**

Risk of bias summary

**Randomised controlled trials**

Cochrane Risk of Bias Tool [15]

| Study                          | Random sequence generation (selection bias) | Allocation concealment (selection bias) | Blinding participants and personnel for all outcomes (performance bias) | Blinding of outcome assessors for all outcomes | Incomplete outcome data for all outcomes (attrition bias) | Selective outcome reporting (reporting bias) | Other sources of bias |
|-------------------------------|---------------------------------------------|-----------------------------------------|-------------------------------------------------------------------------|-----------------------------------------------|---------------------------------------------------|-------------------------------------------|----------------------------|
| Callahan et al., 2006 [21]    | +                                           | +                                      | ?                                                                       | +                                             | +                                                | +                                         | +                                       |
| Thyrian et al., 2017 [26]     | +                                           | -                                      | -                                                                       | -                                             | -                                                | +                                         | +                                       |
| Van den Dungen et al., 2016 [25] | +                                           | -                                      | ?                                                                       | -                                             | +                                                | +                                         | +                                       |
Table 2
Risk of bias summary

Qualitative studies

Based on the CASP Qualitative checklist. [18]

| Criteria | Study | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|----------|-------|---|---|---|---|---|---|---|---|---|----|
| 1. Was there a clear statement of aims? Yes | + | + | + | + | + | + | + | + | + | + |
| 2. Is a qualitative methodology appropriate? Yes | + | + | + | + | + | + | + | + | + | + |
| 3. Was the research design appropriate to address the aims of the research? Unsure | + | + | + | + | + | Unsure | Unsure | + | + | + |
| 4. Was the recruitment strategy appropriate to the aims of the research? Yes | + | + | + | + | + | + | + | + | + | + |
| 5. Was the data collected in a way that addressed the research issue? Yes | + | + | + | + | + | Unsure | Unsure | + | + | + |
| 6. Has the relationship between the researcher and participants been adequately Yes | + | + | + | + | + | + | + | + | + | + |
7. Have ethical considerations been taken into consideration?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of findings?

10. Does the research make a contribution to existing knowledge or understanding?

Table 3
Risk of bias summary

Mixed Methods studies

Mixed Methods Appraisal Tool (MMAT) Version 2018 [17].

| Studies               | Criteria     |
|-----------------------|--------------|
|                       | 1 | 2 | 3 | 4 | 5 |
| Iliffe et al., 2014 [24] | + | + | + | + | + |
| Millard et al., 2011 [3] | + | + | + | NA | - |
| Ollerenshaw et al., 2017 [32] | - | - | + | ? | - |
| Perry et al., 2010 [31] | + | + | + | + | + |

+ Yes    - No    ? Can't tell

Criteria questions

1. Is there an adequate rationale for using a mixed methods design to address the research question?

2. Are the different components of the study effectively integrated to answer the research question?

3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
4. Are the divergences and inconsistencies between qualitative and quantitative results adequately addressed?

5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Table 4
Risk of bias summary
Survey studies

Critical Appraisal of a Survey checklist [16].

| Criteria | Study | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 |
|----------|-------|---|---|---|---|---|---|---|---|---|----|----|
|          | Gilbert et al., 2017 [29] | + | + | + | + | + | - | - | + | + | + |
|          | Manthorpe et al., 2003 [12] | + | + | + | + | - | - | + | + | + | + | ? |
|          | Trickey et al., 2000 [11] | + | + | + | - | + | - | + | ? | - | - | + |

+ Yes - No ? Can’t tell

1. Did the research study address a clearly focused research question?

2. Is the study design appropriate for answering the research question?

3. Is the methods of selection of the subjects clearly described?

4. Could the way the sample was obtained introduce selection bias?

5. Was the sample representative of the population to which the findings will be
referred?

6. Was the sample size based on pre-study considerations of statistical power?

7. Was a satisfactory response rate achieved?

8. Are the measurements (questionnaires) likely to be valid and reliable?

9. Was the statistical significance assessed?

10. Are confidence intervals given for the main results?

11. Could there be confounding factors that haven’t been accounted for?

12. Can the results be applied to other settings?

Table 5
Characteristics of the Randomised Controlled Trials reviewed

| Author, year, country | Aim | Research design | Instruments | Sample and setting |
|-----------------------|-----|-----------------|-------------|--------------------|
| Van den Dungen et al., 2016 [25] The Netherlands, United Kingdom Supplementary papers: Perry et al., 2008 [23] Van den Dungen et al., 2012 [35] | To assess the effect of a two-component intervention of case finding and subsequent care on diagnostic yield of case finding and its impact on the mental health of patients and relatives. | Cluster randomised controlled trial with process evaluation | Cambridge Cognition Examination (CAMCOG) Quality of Life-Alzheimer’s Disease (QoL-AD) Mental Health part of SF-36 (MH5) Short form health survey (SF36) MDS Euro-Qol (EQ5D) 12-item General Health Questionnaire (GHQ12) Short sense of Competence Questionnaire (SSCQ) Neuropsychiatric Inventory (NPI) 12-item Social Support List (SSL12) 15-item Katz questionnaire (Katz15) Mini Mental State Examination (MMSE) | 162 participants in 15 care practices in whom Family Practitioner suspect cognitive impairment without a dementia diagnosis 2 PNs (study over 7 intervention practices) |
To test the effectiveness and safety of Dementia Care management (DCM) in the treatment and care of people with dementia living at home and caregiver burden (when available)

Cluster-randomised intervention trial

Quality of Life (QoL-AD score)
Neuropsychiatric symptoms (NPI score)
Caregiver burden (BIZA-D score)
Anti-dementia drug treatment
Potentially inappropriate medication prescription

634 (mean age = 80 years) people diagnosed as having dementia

407 received the intervention (60.9% female; 50.1% lived alone)
| Callahan et al., 2006 [21] United States |
| Supporting papers         |
| Austrom et al., 2005 [19] |
| Austrom et al., 2006 [20] |
| Austrom et al., 2004 [34] |
| Boustani et al., [33]    |

To test the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer's disease.

**Randomised Controlled Trial**

- Total patient Neuropsychiatric Inventory (NPI)
- Total caregiver Neuropsychiatric Inventory (NPI)
- Cornell Scale for Depression in Dementia (CSDD)
- Telephone Interview for Cognitive Status
- Patient Health Questionnaire-Alzheimer Disease Cooperative Study Group ADLS
- Caregiver Patient Health Questionnaire-9

**N=153 older adults with Alzheimer Disease and their caregivers**

Predominantly ethnic community

- n= 84 intervention of collaborative care management

**Setting** was primary care practices, 1 seven community-based health centres serving medically indigent patients affiliated with university-affiliated urban health care centres

- Three primary care practices at a Veteran Affairs Medical Centre.
Table 6
Characteristics of the Survey/Questionnaire studies reviewed

| Author, year, country | Aim | Research design | Instruments | Sample and (characteristics) |
|-----------------------|-----|-----------------|-------------|-----------------------------|
| Trickey et al., 2000 [11] United Kingdom | To examine the knowledge and attitudes of primary care nurses who undertake the Over-75 Check, towards assessing and managing patients with symptoms of dementia, and to assess their level of support for a clinical practice guideline. | Descriptive | Postal questionnaire survey undertaken of primary care nurses responsible for the Over-75 Check. Questionnaire included -a case vignette for eliciting information about knowledge, attitudes and opinions -demographic information about the nurses, their training -- the practice routine for the Over-75 Check. | 127 (65% response rate) respondents -71% practice nurses -11% health -6% district nurses -12% other All respondents female 75% over 40 32% over 50 18% had completed a post-registration course in nursing people |
| Study                        | Title                                                                 | Objective                                                                 | Method                                                                 | Participants          |
|------------------------------|-----------------------------------------------------------------------|---------------------------------------------------------------------------|------------------------------------------------------------------------|-----------------------|
| Manthorpe et al., 2003 [12]  | United Kingdom                                                       | To explore whether CMHNs (CMHNs), CNs (CNs), and PNs (PNs) have different perspectives on early diagnosis of dementia | Intervention Comparative                                                | 268 nurses (153 CNs, 36 PNs) |
| Supplementary papers         | Downs & Rae, 1996 [46]                                               |                                                                           |                                                                        |                       |
| Supplementary papers         | Iliffe et al., 1999[39]                                              |                                                                           |                                                                        |                       |
| Supplementary papers         | Ilife et al., 2003 [45]                                              |                                                                           |                                                                        |                       |
| Gilbert et al., 2017 [29]    | United Kingdom                                                       | To explore the service use and reported unmet needs of people with dementia recruited a decade apart | Questionnaire Comparative                                              |                       |
| Supplementary papers         | Downs et al., 2006 [40]                                              |                                                                           |                                                                        |                       |
| Supplementary papers         | Illife et al., 2010 [41]                                             |                                                                           |                                                                        |                       |
| Sample 1                     | Central Scotl London 2000-2001 Support pers 122                      |                                                                           |                                                                        |                       |
| Sample 2                     | South-East E 2010-2011 Support pers                                  |                                                                           |                                                                        |                       |
Table 7
Characteristics of Mixed Methods studies reviewed

| Author, year, country | Aim                                                                 | Research design | Instruments                                                                 | Sample and (+characteristics) |
|----------------------|----------------------------------------------------------------------|-----------------|-----------------------------------------------------------------------------|-------------------------------|
| Ollerernshaw et al, 2017 [32] Australia | To explore the awareness and usage of an online Dementia Pathways Tool (DPT) for primary health care practitioners in regional Victoria | Descriptive     | On-line questionnaire (administered through Lime survey) with 40 questions included open and closed questions, Likert scales and multiple-choice questions. Respondents who had not used the DPT only answered questions 1-12. Google Analytics provides information on the usage of on-line tools. | A total of 42 and PNs (21) participated study. All the PNs worked in practices located in regional Western Victoria. |
| Millard et al., 2011 [3] Australia | To explore dementia literacy in a general practice setting and to test whether a waiting room pamphlet would improve patient awareness of dementia risk reduction | Mixed method study that included a questionnaire, a RCT intervention and data from computerised medical records | A 1 page questionnaire was administered to GPs and PNs exploring dementia literacy and included epidemiological questions, multiple choice questions and free text string answers. | 621 patients in the RCT study: 265 GPs and 26 F completed the questionnaire. 558 patients: 64% female; age 50-59 years sampled from practices in 1 |
Patients, aged over 30 years, in the waiting room were administered a 1 page questionnaire to identify sources, and adequacy, of dementia and risk reduction knowledge. The intervention, a risk reduction education pamphlet, were administered to the patients using a simple randomisation with 50% of the participants receiving the pamphlet with questionnaire and 50% receiving the questionnaire only.

Computerised medical records were checked for dementia diagnosis and completion of a MMSE.

63 patients (57% female; age of 70-79 were sampled from 3 practices in England. 106 GPs (57 males; 49 females) were recruited from 50 different sites in Australia and 21 GPs (9 males; 12 females) were located in England. 26 PN were in the study were female were located in practices in Australia and 1 in England.
| Authors | Country | Objective | Methodology | Inclusion, exclusion, and exclusion criteria | Description |
|---------|---------|-----------|-------------|---------------------------------------------|-------------|
| Perry et al., 2010 [31] | Netherlands | To construct a set of quality indicators (QIs) for dementia diagnosis and management in a primary care setting. | Mixed methods RAND modified Delphi including a postal survey, stakeholder consensus meeting, a scientific expert consensus meeting and demonstration project | Postal survey (9-point Likert scale, GPs and PCNs assessed relevance, feasibility, informal support person(s) assessed relevance of QI only) | Participants: postal survey (67), primary nurses (21) in informal care (34). Eight national dementia experts (1 geriatrician, 2 GPs, 2 nursing scientists, 1 medical sociologist, 1 psychologist, 2 geriatric nurses) in expert panel and scientific consensus meeting. 1 GP, 2 primary care nurses and 4 informal support persons in stakeholder consensus meeting. Thirteen GPs in the demonstration project. |
| Iliffe et al., 2014 [24] | United Kingdom | To adapt a US model of primary care-based case management (PREVENT) for people with dementia and test it in General Practice | Mixed methodology comprising case studies of case management implementation in four General Practices | Case study - number of case of dementia - unmet needs identification - actions taken to meet needs - contacts with case managers and other health professionals | Potential participants were identified from the QOF register and supplementary services. Participants were community dwelling patients with dementia who were receiving general practice and a family support person(s) and who were not receiving specialist care. |

Supplementary papers
- Bamford et al., 2014 [49]
- Iliffe et al., 2014 [48]
- Waugh et al., 2013 [47]
patients, support person(s), local NHS and other stakeholders, and case managers coordination.
A total of 28 support person(s) were recruited across four practices; one rural, one inner-city and two urban.
PNs undertook the case manager role in rural and inner-city practices and were allocated one session per week for case management by their respective practices. A social worker worked full-time between the two urban practices.
Table 8
Characteristics of the qualitative studies reviewed

| Author, year, country | Aim                                                                 | Research design                      | Instruments                                                                 | Sample size (+characteristics) |
|-----------------------|----------------------------------------------------------------------|--------------------------------------|-----------------------------------------------------------------------------|---------------------------------|
| Dodd et al., 2014 [27] | To contrast participant’s experiences of primary care led dementia services in Bristol with existing secondary care based memory services | Qualitative participatory study       | Semi-structured interview developed by professional and peer panels.          | Purposive A total of participators from primary and secondary care. This included health care professionals, patients and support person(s). A total of 23 participants were recruited from one of the eleven of the 53 GP practices in Bristol offering primary care led dementia services. GPs were invited by email to participate in the study. Eligible patients were people of any age who had been diagnosed within the previous six months with any form of dementia (MCI excluded) and were able to provide consent to participate. The same criteria applied to patients recruited from secondary care. Health care professionals, patients and support person(s) were included. The interviews lasted, on average, 20 minutes, varying in duration from 10 to 44 minutes. |
| Reference                          | Country          | Objective                                                                 | Methodology          | Sample Size                                                                 |
|-----------------------------------|------------------|---------------------------------------------------------------------------|----------------------|-----------------------------------------------------------------------------|
| Dodd et al., 2016 [28]            | United Kingdom   | To provide a qualitative analysis of the experiences of health care professionals, patients and their families, of the new process of assessment, diagnosis and treatment of dementia within a primary care service. | Interview            | 23 surgeries in the South Gloucestershire area participated in the study. Recruitment was via email invitation directly or telephone conversations with practice managers. Four patients, three caregivers and eight health care professionals were interviewed by peer researchers (caregivers). |
| Manthorpe et al., 2003 [30]       | United Kingdom   | To explore the implications of the early recognition of dementia for inter-professional working. | Focus group interviews | Conveniencesample. Nearly 10 (247), CM practice (238), CNs (146), workers a home staff in four focus groups in each workshop. The workshops were open to all community health professionals who paid a small enrolment fee to the local Alzheimer's Society or |
Figure 1
Study selection

Records identified through database searching (n = 1875)

Records after duplicates removed (n = 1802)

Records screened in (n = 68)

Records excluded (n = 1734)

Additional records identified through other sources (n = 3)

Full-text articles assessed for eligibility (n = 71)

Full-text articles excluded, with reasons (n = 58)

Total studies included (n = 13)
Including quantitative, mixed methods and qualitative studies

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses. The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed.1000097
