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

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Abstract

Background The potential value of expanding the Practice Nurse role to include the recognition and management of dementia has been acknowledged. 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 literature to identify existing and potential roles of Practice Nurse’s in the delivery of care to people affected by dementia and to describe the characteristics and effectiveness of nurse interventions in dementia models of care.

Methods The PRISMA statement was used as a guide to systematically review the evidence for roles and characteristics of the Practice Nurse in the delivery of dementia care. A comprehensive literature search of seven electronic databases and Google scholar identified relevant original research published in English between January 2000 and January 2019. Thirteen articles met the inclusion criteria and were extracted into the Covidence software for analysis.

Results The heterogeneity of the included studies purpose, design and outcomes measures and the diversity in health systems and primary care nurses scope of practice made it difficult to synthesise the findings and draw conclusions. The heterogeneity did, however, provide important insights into the 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. These included 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 Embedding an evidence-based model that describes 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

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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 (5). 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 with people with cognitive decline through routine primary care treatment, health assessment, chronic disease management and health promotion activities.

The potential value of expanding the PN role to include the recognition and management of dementia has been acknowledged [4, 12]. 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.

There has been no systematic review of the evidence on the role of the PN in dementia care delivery to date, therefore the aim of this review is to examine published literature to investigate the Practice Nurse role in the delivery of care to people affected by dementia.

This paper systematically reviews published 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?

The 27 item PRISMA-P Checklist [13] was used to guide this systematic review. The checklist includes items deemed essential for systematic review reporting [14].

**Methods**

**Eligibility criteria**

All published 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 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, CINHAHL (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
that may not have been identified in the primary search.

**Search strategy**

Original searches were carried out on the 24\textsuperscript{th} 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 1\textsuperscript{st} 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 memor 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 were 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 or unsure. The irrelevant papers were discarded from the selection process. Published papers were retrieved for abstracts categorised as relevant or unsure. The retrieved papers were then reviewed and those deemed as 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. This information is described in Tables 5-8.

**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]. Mixed methods data was appraised using the Mixed Methods Appraisal Tool (MMAT) Version 2018 [17]. Risk of bias in qualitative studies was appraised using a tool based on the Critical Appraisal Skills Programme (CASP) Qualitative checklist [18]. The assessment criteria for each of the quality appraisal tools used is described in...
Tables 1-4.

**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. Synthesis of data from studies so diverse in study questions, methodologies, nurse scope of practice and health systems is inherently problematic and it was not possible to sensibly categorise findings into themes. A pragmatic approach to reporting the findings of such heterogeneous studies by aggregating studies by methodology was therefore undertaken.

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 as separate papers due to the reporting of different outcome measures the paper with the most detailed analysis relevant to the aims of this systematic review was included. The other papers adding information to the paper included in this systematic review 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 - 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 1870 references (Figure 1). After removal of duplicates 1802 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 poster abstracts and the studies not published, and 17 papers were removed as they were multiple publications reporting on the same intervention and were included as supplementary papers. Three were duplicate studies [19-21] and two studies [22,23] were excluded as the outcomes had not been published. The authors of these studies were contacted. 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).

Due to the heterogeneity of the studies a pragmatic approach to reporting the findings of was taken by aggregating studies by methodology. The heterogeneity did provide important insights into the variety of involvement of primary care nurses in delivering dementia care.

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 [3,11,12]. 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 interventions and outcomes are described in Tables 5 - 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]. In addition to training, in the model of care described in Callahan et al., [21] the nurse received weekly support from a geriatrician, geriatric psychiatrist and a psychologist.

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] recommend that collaborative care with nurses in primary care deserves further exploration.

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 community 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 CMHNs. 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. The Over-75 year health check is an annual health check including a mental assessment for people aged over 75 years [11].

Gilbert et al., [29] reported that support person(s) were increasingly contacting a PN for support with less evident use of CNs, health visitors and CMHNs. 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.

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 [31]. 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, Iliffe et al., [24] suggest that case management does not fit easily into practice routines and that it was not substantially beneficial for patients and support person(s).

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.

Risk of bias

The methodological quality varied across the studies (Tables 1 -4). The qualitative studies 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 and no sample size was based on consideration of statistical power.

In addition to these limitations, Callahan et al., [21] describe their study as unable to identify which of the subcomponents of the intervention were most effective in achieving the outcomes. Van den Dungen et al., [25] reported the rates of MCI or dementia identified were lower than expected. The authors state 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 [25]. 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 [26].

Trickey et al., [11] describe a methodological limitation of using a vignette that may more correctly explore current practice rather than knowledge and attitudes [11]. Iliffe et al., [24] report time constraints for the case management role of the PNs may have meant there was insufficient time to show the potential of case management.

Discussion
This systematic review of the published 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) evaluated thirteen studies.

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 heterogeneity of studies’ purpose, design, and outcomes measures make it difficult to synthesise the findings and draw conclusions. However the heterogeneity did provide important insights into the different roles of nurses and advances understanding about the intervention itself rather than just its effectiveness.

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 case 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 [25, 27]. 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 PN 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 [11] 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 [24, 27, 29]. 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.

**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 primary care nurse models of dementia care provision. The different studies examined different aspects of the PNs role in relation to dementia. Differences in scopes of nurse practice and health systems mean one model of care may not be appropriate. However this systematic review provides insights into what components of a model of care may be effective. These roles included care management, identification and/or management of behavioural and psychological 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 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.

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

**List Of Abbreviations**

**APNA**  Australian Primary Health Nurse Association  
**CMHN**  Community Mental Health Nurse  
**CN**  Community nurse  
**DCM**  Dementia Care Management  
**FP**  Family Practitioner
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.

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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.

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### Tables

#### Table 1

**Risk of bias summary**

**Randomised controlled trials**

Cochrane Risk of Bias Tool [15]

|                           | 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 bias |
|---------------------------|---------------------------------------------|----------------------------------------|------------------------------------------------------------------------|-------------------------------------------|------------------------------------------------------|-------------------------------------------------|-------------------|
| Callahan et al., 2006 [21]| +                                          | +                                     | ?                                                                      | +                                        | +                                                    | +                                               | +                 |
| Thyrian et al., 2017 [26] | +                                          | -                                     | -                                                                      | -                                        | -                                                    | +                                               | +                 |
| Van den Dungen et al., 2016 [25] | +                                      | -                                     | -                                                                      | ?                                        | -                                                    | +                                               | +                 |

- High risk of bias         + Low risk of bias         ? Unclear risk of bias
Table 2

Risk of bias summary

Qualitative studies

Based on the CASP Qualitative checklist. [18]

| Study                  | Criteria          | 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  | 10 |
|------------------------|-------------------|----|----|----|----|----|----|----|----|----|----|
| Dodd et al., 2014 [27] |                   | +  | +  | +  | +  | +  | +  | +  | +  | +  | +  |
| Dodd et al., 2016 [28] |                   | +  | +  | +  | +  | +  | +  | +  | +  | +  | +  |
| Manthorpe et al., 2003 [30] |               | +  | +  | +  | +  | +  | Unsure | Unsure | +  | +  | +  |

+ Yes - No ? Unsure

Criteria

1. Was there a clear statement of aims?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between the researcher and participants been adequately considered?
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 | 12 |
|-------|---|---|---|---|---|---|---|---|---|----|----|----|
| 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 | Sa (+) |
|-----------------------|-----|-----------------|-------------|--------|
| Van den Dungen et al., 2016 [25] | | | Cambridge Cognition Examination (CAMCOG) | 16 |
| | | | Quality of Life-Alzheimer’s Disease (QoL-AD) | |
| | | | Mental Health part of SF-36 (MH5) | |
| | | | Short form health survey (SF36) | |
| Location | Study Title | Study Details | Outcome Measures | Control Group Details |
|----------|-------------|---------------|------------------|-----------------------|
| The Netherlands, United Kingdom | Supplementary papers: | Perry et al., 2008 [23] | 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 | 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) |
| | | Van den Dungen et al., 2012 [35] | | |
| Germany | Thyrian, J.R. et al., 2017 [26] | 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 people diagnosed with dementia, 407 received the intervention |
| | Supplementary papers: | Dreier et al., 2016 [38] | | |
| | | Thyrian et al., 2012 [37] | | |
To test the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer's disease.

Supporting papers
- Austrom et al., 2005 [19]
- Austrom et al., 2006 [20]
- Austrom et al., 2004 [34]
- Boustani et al., 2005 [33]

| Author, year, country | Aim | Research design | Instruments |
|-----------------------|-----|----------------|-------------|
| Callahan et al., 2006 [21] United States | 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 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 |
| Austrom et al., 2005 [19] | 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 caregiver Neuropsychiatric Inventory (NPI) |
| Austrom et al., 2006 [20] | | | Cornell Scale for Depression in Dementia (CSDD) |
| Austrom et al., 2004 [34] | | | Telephone Interview for Cognitive Status |
| Boustani et al., 2005 [33] | | | Patient Health Questionnaire-Alzheimer Disease Cooperative Study Group ADLS |
| | | | Caregiver Patient Health Questionnaire-9 |

### Table 6
Characteristics of the Survey/Questionnaire studies reviewed

| Author, year, country | Aim | Research design | Instruments |
|-----------------------|-----|----------------|-------------|
| Trickey et al., 2000 [11] United Kingdom | To examine the knowledge and attitudes of primary care nurses who undertake | | Postal questionnaire survey of primary care nurses responsible for the Over-75 Check |
| | | | -127 resp | -71% nurs | -11% | -6% |
| **Manthorpe et al., 2003 [12]** | **United Kingdom** | **To explore whether Community Mental Health Nurses (CMHNs), Community Nurses (CNs), and PNs have different perspectives on early diagnosis of dementia** | **Intervention** | **Comparative** |
|---|---|---|---|---|
| **Supplementary papers** | **Downs & Rae, 1996 [46]** | | | |
| | **Iliffe et al., 1999 [39]** | | | |
| | **Iliffe et al., 2003 [45]** | | | |
| **Gilbert et al., 2017 [29]** | | | | |

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**
  - Questionnaire included
  - a case vignette for eliciting information about knowledge, attitudes and opinions
  - demographic information

- **Comparative**
  - Questionnaire derived from the Stirling Service Development Centre
  - asked the nurses about clinical role, experience, case load, epidemiological and clinical knowledge, confidence in recognising the dementias and perceived difficulties in providing care for people with dementia

- **268 nurses (79 CMHNs, 153 CNs, 36 PNs)**

Both samples have similar demographics and the people with dementia had similar degrees of disability and engagement with community services.
Table 7
Characteristics of Mixed Methods studies reviewed

| Author, year, country | Aim | Research design | Instruments | Sample size
|-----------------------|-----|-----------------|-------------|---------------|
| 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 | A to 558 patients (36% male, 64% female; median age 64% female; median age
| | | | Google Analytics provides information on the usage of on-line tools. | 2017 [32] |

To explore the service use and reported unmet needs of people with dementia recruited a decade apart

The questionnaire covered demographics and capabilities of the person with dementia as perceived by the support person(s) assessed across nine different activities of daily living
| Study | Country | Objective | Methodology | Data Sources |
|-------|---------|-----------|-------------|--------------|
| 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: questionnaire, RCT and data from computerised medical records | Questionnaire for GP/ PN, Questionnaire for waiting room patients, Computerised medical records. |
| Millard & Baune, 2009 [50] | Australia | | | 50–5 sam in 1-63 yrs |
| 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, stakeholders consensus meeting, a scientific expert consensus meeting and demonstration project | Postal survey, GPs and PCNs assessed relevance, feasibility of QIs, Mixed methods RAND modified Delphi, Inclusion, exclusion, revision of QIs by consensus at stakeholder and scientific expert meetings, Demonstration project |
| | | | | 26 F the fem loca Ausl |
| | | | | GPs info |
| | | | | Eight exp GPs mec psy nurs and mee |
| | | | | 1 Gl info in st mee |
| | | | | Thir dern |
| | | | | GPs recr |
| Iliffe et al., 2014 [24] | United Kingdom | Tested adherence rates and discriminative validity. |
|-----------------------|---------------|--------------------------------------------------|
| Supplementary papers  |               |                                                  |
| Bamford et al., 2014 [49] |             |                                                  |
| Iliffe et al., 2014 [48] |             |                                                  |
| Waugh et al., 2013 [47]  |               |                                                  |

To adapt a US model of primary care-based case management (CM) (PREVENT) for people with dementia and test it in General Practice

Mixed methodology comprising case studies of CM implementation in four General Practices and Interview with patients, support person(s), local NHS and other stakeholders, and case managers

CAREDEM Case management

Participants were community dwelling patients with dementia who were living at home with a family support person(s) and who were not receiving specialist care coordination.

A total of 28 dyads and 1 support person(s) were recruited across four practices; one rural, one inner-city and two urban.

Table 8
### Characteristics of the qualitative studies reviewed

| Author, year, country | Aim | Research design | Instruments |
|-----------------------|-----|----------------|-------------|
| Dodd et al., 2014 [27] United Kingdom | 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. Questions were organised under four main themes (1) GPs making an independent dementia diagnosis (2) GPs working with memory nurses (3) patients and support person(s) experience, and (4) post-diagnostic support. The interviews lasted, on average, 20 minutes. |
| 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 | Semi-structured interview |
|---|---|---|
| Interview | Descriptive | |

**Interview**

Descriptive

**Semi-structured interview**

Manthorpe et al., 2003 [30]
United Kingdom

Supplementary papers
Iliffe et al., 1999 [39]
Iliffe et al., 2003 [45]

To explore the implications of the early recognition of dementia for inter-professional working.

Focus group interviews

Nominal group technique

Figures
Figure 1
Study selection

Records identified through database searching
(n = 1870)

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)
Figure 1

Study Selection

Supplementary Files

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