

**Environmental Scan in support of 2012 CBPHC Team Grant**

## **Background Study 1**

### **Primary healthcare (PHC) for people with dementia and their caregivers in rural and remote areas: perspectives of health region directors**

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## **PURPOSES OF THE STUDY**

We undertook this study to explore issues associated with primary healthcare (PHC) for people with dementia and their caregivers in rural and remote areas from the perspective of Saskatchewan health region directors. Specifically, we focused on the issues of gaps and challenges in primary healthcare, possible solutions to these challenges, and potential interventions or models of chronic disease management for rural and remote patients with dementia and their caregivers.

## **ETHICAL APPROVAL**

This study received ethics approval from the University of Saskatchewan Behavioural Research Ethics Board (BEH #11-192).

## **SELECTING PARTICIPANTS**

A Saskatchewan Health staff member provided a list containing the names and contact information for 14 Chronic Disease contacts representing 13 health regions across Saskatchewan (Regina Qu'Appelle health region had two contacts). From Saskatchewan Health's website, we obtained a similar list containing the names and contact information of 13 PHC directors for 13 health regions. In six health regions, one individual occupied the positions of both PHC director and Chronic Disease director. Our study sample included all 21 PHC directors and Chronic Disease directors representing 13 Saskatchewan health regions.

## **DATA COLLECTION**

In August, 2011, we emailed an invitation to participate in our research study to a sample of 21 PHC and Chronic Disease directors representing all of Saskatchewan's 13 health regions. Of 21 directors contacted, 10 directors representing eight of the province's 13 health regions completed interviews (48% response rate). Data were collected by semi-structured telephone interviews conducted in August and September, 2011.

## **INTERVIEWS**

The telephone interviews were between eight and 20 minutes in duration. Each interview was audio-recorded and transcribed immediately by a research assistant. We followed a semi-structured interview guide containing six questions, and discussed other topics as they emerged during the interview. Once all of the interviews were conducted and transcribed, we analysed participants' responses to the three questions marked by an asterisk. In the following sections, we present the findings from this analysis.

The semi-structured interview guide contained these six questions:

1. What is your job title?
2. What is your role (how would you describe your day-to-day responsibilities)?
- \*3. From your perspective, what are the key gaps (issues/challenges) in Primary Healthcare for people with dementia and their caregivers in the rural and remote areas of your health region?
- \*4. What needs to be done to improve Primary Healthcare for people with dementia and their caregivers in the rural and remote areas of your health region?
- \*5. Are there models of chronic disease management in your community that could be adapted to dementia care (e.g., diabetes)?
6. Are you aware of any continuing education opportunities in dementia care for primary healthcare professionals in your health region?

## RESULTS

### Gaps

Based on participants' descriptions of the gaps in primary healthcare for people with dementia and their caregivers in rural and remote areas (i.e., question #3), we identified three broad categories to guide our analysis: patients/caregivers, healthcare professionals, and health region.

#### *Patients/Caregivers*

The gaps associated with patient/caregiver issues mainly centred around the topic of transportation and service access. Several participants referred to difficulties faced by patients in travelling to access services and the lack of services (e.g., specialists) closer to home. One participant referred to the challenge of travelling significant distances to access health services faced by most people living rural and remote, then drew attention to the magnification of these problems on First Nations reserves:

“...we have some people that are an hour away or more from any medical care. So part of that is the isolation...we have lots of First Nations in our health region, many reserves. The gaps there I think are quite huge as far as transportation and resources on reserve and financial resources and human resources.” (ID1005)

#### *Healthcare Professionals*

Participants indicated that one of the challenges associated with primary healthcare was a lack of knowledge among healthcare professionals concerning dementia care, specifically diagnosis, management, and availability of community resources. One participant also observed that information overload among family physicians interfered with following best practice guidelines, such as completing flowsheets. Knowledge regarding dementia care was identified as an issue particularly among family physicians new to their health region and international medical graduates:

“...they come here and our chronic diseases are diseases of excess, like heart disease, diabetes and because people live so long, they're often not familiar with how we approach dementia care in Canada. And I think there sometimes is a gap in terms of treatment and follow through.” (ID1008)

#### *Health Region*

The main gaps at the health region level identified by participants included programs and services, staffing, health region priorities, and geography.

With respect to programs and services, participants reported that dementia-related and dementia-specific resources/services were insufficient. Participants noted that the rural communities in their health regions lacked adequate day programs to offer respite to caregivers, which in turn resulted in fewer people with dementia able to remain in their homes before moving into long-term care.

“...there probably is just a lack of support period and resources...I don't think in all communities but in some communities there is some day respite...other than that I don't think there is anything too much.” (ID1006)

Staffing shortages were regarded as the most significant issue affecting primary healthcare. Insufficient programming and services for people with dementia and their caregivers were linked to staffing shortages by many participants. Consequently, expert resources were scarce, home care and respite services were understaffed, few family physicians were taking new clients, and patients faced long wait times to see their primary healthcare provider. Furthermore, most participants reported that their health regions faced human resource shortages:

“In the rural (areas) sometimes it’s related more to human resources, like unfilled positions or not being able to replace staff cause there’s only one person in that area. So it’s not anyone’s not trying to provide the service, it’s lack of human resources.” (ID1003)

It appeared that in the rural areas of a few health regions, dementia had not yet been recognized as a public health concern requiring attention. This observation was evident in a participant’s comment that NPs and FPs had not communicated any concerns regarding people with dementia to health region representatives. Participants also noted that dementia had not been identified as an issue in their health region proper, was not on their health region’s ‘priority list’, and their health region did not have a specific focus on dementia care.

The sparse population of rural communities across health regions presented challenges to offering local health services, however, centralizing services in a few communities required patients and families to travel significant distances. One participant noted that the population and geography of their health region somewhat dictated the dementia-related services offered:

“...they (people with dementia in rural and remote areas) would be so geographically spread out that it would be hard to actually do anything specifically for that population. And so you would see it quite sporadic. Like you might have something going on here but it is such a small number of people that you couldn’t benefit or expand it the way you potentially could in a site that was more densely populated. So we’ve had to look at things like overall chronic condition programs so that you don’t have to wait for that one specific population that it might be that you might have a program that is more general.” (ID1007)

### **Suggestions for improvement**

Participants’ suggestions for improving primary healthcare for people with dementia and their caregivers in rural and remote areas (i.e., question #4), were collapsed into three categories to frame our analysis: services and programs, education and awareness, and technology and innovation. Beyond ‘what’ should be improved, in some cases, participants also specified ‘who’ should be involved in the process of improvement.

#### *Services and programs*

Suggestions for improvement focused mainly on addressing the gaps in services and programs for rural and remote dwellers by increasing staffing, improving access, and reorganizing services. Specifically, participants referred to the need for more healthcare providers as well as more healthcare teams to meet demand as well as better serve current patient needs. The services of home care, respite care, and day care all required improvement, particularly due to staffing shortages. Further, the importance of specialist services and the disadvantage of living rural when specialist access is necessary was highlighted by participants. One participant noted that specialty nurses might fill the gap:

“... if there were specialty doctors that could support the local GPs on how to manage dementia locally. I'm not sure in our region whether anybody in long term care or acute care would consider themselves a specialist in dementia, that would be something I don't know the answer to. So local support by a specialist, whether it's a specialty nurse - I don't think we'd ever locally get a physician specialist but local support would be great.” (ID1015)

One participant also noted that implementing a standard process in their health region would improve care for persons with dementia and their caregivers:

“Well I think that we need to actually create such a structured process and have a standard assessment tool that we use throughout so that we're all speaking the same language and then have information available as to what is available in our area for those services and what are the options.” (ID1002)

#### *Education and awareness*

Making advances in education and increasing awareness among healthcare professionals were clearly important strategies for improvement for some participants, one of whom indicated that dementia was more likely to be considered part of normal aging than viewed as a health issue. This particular participant suggested:

“...we've got (number) continuing nurse educators and this is something that they could be helping with. At least in the education and the awareness.” (ID1004)

Awareness among the general public was also targeted for improvement:

“I think dementia is sort of off the radar. I think it has to be more front and centre, I think people have to really know about it, both from the health providers have to know about it more and then the public have to know about it more.” (ID1016)

#### *Technology and Innovation*

Participants drew attention to the contributions that technology and innovation might make to closing the gaps in primary healthcare. One participant commented on the importance of integrating technology into primary care so as to improve specialist access for rural dwellers with dementia in particular:

“I think if we had investment in infrastructure for videoconferencing so that we could actually videoconference with a lot of the gerontologists ... so that we don't have to transport clients out of their community with dementia to the specialists. And even to expand on the telehealth, the videoconferencing technology not only for gerontologists but for other specialists, because it's very difficult with a demented patient client to take them to see a specialist if they live in a rural area. You know it's very upsetting, it's hard and a lot of times I don't think they actually get the care they need because it's just too hard to do it. So I wish we were using technology to really move forward and to facilitate those types of consults.” (ID1008)

Developing partnerships among organizations and individuals who have not traditionally worked together was also offered as a solution to improving primary healthcare for this group. However, the challenges of innovation were noted by one participant:

“Like we're doing a lot of things in primary health care, we're bringing community and community-based organizations and government agencies together but that's not easy because some of them say well they don't see their role or they don't normally work in that way and we're going ‘well you know what it's working here, why don't you come and take a look.’ So a lot of times it's just a matter of just trying to get people to see things differently. Especially that whole team concept. It might take awhile to get it going but in the long run it'll be huge.” (ID1007)

### **Models of chronic disease management**

Participants were asked whether there were models of chronic disease management in their community that could be adapted to dementia care. During the interviews, we further expanded this question to allow participants to discuss models or interventions that they were aware of that might be used to improve primary healthcare services for people with dementia and their caregivers in rural and remote areas. Participants identified two models of care as possibly feasible for dementia care: Wagner model of chronic disease management/Health Quality Council (HQC) collaborative and Livewell chronic disease management program. Two interventions were also described as potentially applicable to dementia care: a point of entry team approach and a nurse case manager role.

#### *Wagner model of chronic disease management/HQC collaborative*

The model of care mentioned most frequently by participants was the Wagner model of chronic disease management. Participants from some health regions were already providing services to patients with specific chronic conditions, as well as their caregivers, based on this model. The Wagner model is a key element of the Saskatchewan Chronic Disease Management Collaborative developed by the Saskatchewan Health Quality Council (HQC). Since 2005, HQC has implemented collaboratives in participating health regions across Saskatchewan, focused on depression and chronic obstructive pulmonary disease (COPD), coronary artery disease, diabetes, and improving office efficiency (Health Quality Council, 2007).

“If I live say 15 minutes outside my health centre or 15 minutes outside my community that I'm closest to, I travel in for groceries and gas. But I also may go see the diabetes team when they're there or the physician when he comes on Wednesdays...so I think people are used to that type of travel. It's when you ask them to travel up to an hour or two hours to go in for something and then come back, it's a little different. So what we've tried with the diabetes program for sure is to move the teams and train an established team across the region so that people travel to their normal place of getting care and there's a diabetes team there to help them.” (ID1016)

#### *LiveWell chronic disease management program*

Several participants also referred to the LiveWell program as potentially useful for caregivers of people with dementia. Given that the program promotes self-management and focuses on emotional aspects, yet is not specific to a chronic condition, participants felt that the program would be beneficial to caregivers.

“...it really is a self-management peer led program where folks go through the 8 week series of classes and they usually have more than one chronic condition and some of these folks end up to be peer leaders so they come back and either volunteer their time or get an honorarium for helping run the classes with their community...I think this would apply very well in the area of dementia, particularly for caregivers.” (ID1001)

#### *Point of entry team approach*

One participant described a ‘point of entry team-based approach’ that delivered services in healthcare teams to more than one family member at once. As the participant explained, a woman and her child or a woman and her mother could receive services at the same appointment, from the most appropriate healthcare provider(s) at that time:

“So if Mrs. Smith happened to bring in her mother that had dementia... she’d (case manager) pull in the services that were there...maybe coordinate a videoconference with a specialist at another site if need be...”(ID1008)

#### *Nurse case manager role*

One approach that was also identified as feasible for people with dementia was creating a role for a nurse case manager who would be responsible for facilitation and follow-up, particularly in rural primary healthcare:

“...who would do a lot of the follow-up and people will come to see her, they might not get to see the doc that day or the NP but they could...come and see someone and that’s generally the nurse case manager. And she facilitates the things and makes sure the continuum of care gets followed through on or makes sure people have seen the specialist, they did hear back, just that kind of a role.” (ID1006)

## **SUMMARY**

The results of the current study suggest that people with dementia and their caregivers in rural Saskatchewan face substantial challenges in obtaining primary healthcare services. Study participants (10 PHC and Chronic Disease directors representing eight health regions) provided valuable insight into these issues.

At the patient/caregiver level, challenges in primary healthcare included transportation and service access; at the level of healthcare professionals, the issues identified were lack of knowledge and information overload; and at the health region level, participants pointed to gaps associated with programs and services, staffing, health region priorities, and geography.

Participants also advanced several suggestions for improving primary healthcare for rural people with dementia and their caregivers. These suggestions consisted of improving services and programs by increasing staffing, improving access, and reorganizing services; attending to education and public awareness; and investing in technology and innovation.

Participants put forth four models and interventions as highly applicable for delivering services to rural people with dementia and their caregivers. These suggestions included the Wagner model of chronic disease management/Health Quality Council (HQC) collaborative, Livewell chronic disease management program, a point of entry team approach, and a nurse case manager role.

The results of this study will aid in developing interventions in primary healthcare for people with dementia and their caregivers in rural Saskatchewan. This study suggests that these interventions should take into account the unique challenges of rural living, and consider improvements that are innovative yet feasible at the health region level.

## **REFERENCES**

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## **Background Study 2**

### **A systematic review of primary care-based dementia case management models**

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## PURPOSE OF THE STUDY

The aim of this review is to identify interventions in care provision that offered collaborative or case/care management in relation to persons with dementia or Alzheimer's disease, in primary healthcare settings.

## METHODS

### Search strategy

Three databases were searched between August 15, 2011 and August 18, 2011. The databases included Medline, PsycInfo, and EMBASE. Search terms for all databases included: (primary care or general prac\* or family prac\*) and (dementia or alzheimer\*) and (nurs\* or case manage\* or care manage\* or care model or collaborative or memory clinic). An asterisk indicates that the search included all terms that began with that root. The search was limited to English language studies published between 1990 and 2011.

### Inclusion criteria

Eligible studies included only published peer-reviewed original articles. Studies were eligible if they examined care provision in relation to persons with dementia or Alzheimer's disease, were relevant to service provision within primary care settings, and explored collaborative or case/care management that supplemented dementia care provided by family physicians or general practitioners. Excluded from review were dissertations, editorials, book chapters, book reviews, letters to editors, and commentaries.

### Data extraction

One reviewer (JK) extracted data from each study. Extracted data were verified by DM, and included details regarding the study objectives, design and participants, details about each intervention and duration of the intervention or study, healthcare providers involved in the study, outcome measures, and results.

## RESULTS

As shown in Figure 1, the database search resulted in 552 articles identified for review. Two hundred and eight-six (286) articles were excluded on the basis that they were duplicate records. DM and JK each reviewed all of the remaining 266 abstracts. After review, 202 abstracts were excluded because the studies did not meet the inclusion criteria: a) peer-reviewed original article, b) design includes a health service intervention, and c) relevant to primary care, dementia care, and dementia case management/collaborative care. Sixty-four (64) articles were subsequently retrieved and reviewed in full by both reviewers, of which 46 papers were excluded because they did not meet the inclusion criteria. The remaining 18 studies met our inclusion criteria.

The current review includes 18 papers with samples that were comprised primarily of persons with dementia, caregivers (unpaid, family), and/or healthcare professionals. Nine of the included studies were conducted in the US, five in the UK, two in Canada, one in the Netherlands, and one in Thailand. All of the studies were conducted in urban settings.

The 18 studies included in this review are summarized in Table 1. In the following sections, we report on the *intervention* used in each study; the *healthcare providers* that were employed to provide the intervention described in each study; the *outcome measures* used to evaluate the intervention or monitor patient/caregiver care; and the *results* of each study as they pertain to the intervention.

## **Intervention**

The interventions in the studies included in this review covered four major components of dementia care provision: patient assessment, diagnosis, and patient/caregiver management; patient or caregiver support; patient or caregiver follow-up; and education/training. The role of web-based software in supporting dementia care also appeared to be an emerging part of dementia care.

Patient assessment, diagnosis, and patient/caregiver management were the major areas of focus for researchers. Patients were assessed or diagnosed as part of the intervention in 12 studies (2-9,11,12,14,17). Patient/caregiver management was a component of the intervention, or recommendations for patient management were communicated to the FPs/GPs of patients, in all 18 studies.

Studies that reported on interventions incorporating individual support to patients or caregivers (n=10) were more common than those that offered group support (n=5). Specifically, patients were provided individual support in five studies (2,4,10,14,18) and group support in two studies (1,2). Caregivers were provided individual support in seven studies (1,2,5,8,9,15,18) and group support in five studies (1,2,4,5,15).

Several studies reported that first patient/caregiver follow-up occurred before the one-month point: first follow-up to the patient or caregiver was provided by two weeks in four interventions (1,4,7,10), by one month in two interventions (9,17), and after one month in four interventions (2,3,5,12). Seven studies did not report the time elapsed to first patient/caregiver follow-up (6,8,11,13-15,18) and one study did not provide patient/caregiver follow-up (16).

Education and training was a key component of interventions in 11 studies, particularly for caregivers and healthcare providers. Education/training was provided to caregivers in seven studies (1,4,9,13,15,17,18), to FPs/GPs in five studies (5,6,13,16,17), and to patients in two studies (1,13).

Although only four studies employed web-based software to facilitate care (6,8,16,17), the use of technology to support and improve dementia care is likely to grow in the future.

## **Healthcare providers**

The healthcare providers that delivered or received healthcare services as part of interventions in this review included both primary care providers (professionals) and specialists.

The healthcare professionals included in the majority of interventions (n=13) were FPs/GPs (1,3-6,8,9,11-14,16,17). Nurses were integral to the intervention in nine studies (1,3,4,6,8,11,12,14,16), and social workers in eight studies (3,5,7-9,12,14,17). Two interventions included pharmacists (3,12), and one study each involved a physician's assistant (6), a health visitor/practice liaison clinician (11), and a social services home care co-ordinator (14).

Most interventions employed a geriatrician, geriatric psychiatrist, or psychologist. A geriatrician took part in the interventions in three studies (1,4,12), and two studies each involved a consultant in old age psychiatry (11,14), geriatric psychiatrist (1,4), specialist in dementia (16,18), and internist (3,6). Three studies involved psychologists (1,3,4), and one study each included a neurologist (5), physiotherapist (11), and speech language therapist (9).

Care/case managers were integral to the majority of the interventions reviewed. Specifically, a care/case manager or care/case co-ordinator occupied an on-going role in 12 studies (1,4,5-9,11,14,15,17,18).

## **Outcome measures**

Outcomes were measured as part of the intervention in 14 studies, and not measured in four studies (1,10,13,14). Outcome measures fell within the categories of patients, caregivers, healthcare providers, and service outcomes.

### *Patients*

Among patients, the most common outcome measure was cognitive status, followed by measures of depression, activities of daily living, satisfaction with healthcare, and use of healthcare services.

Patients' cognitive status was assessed with the Mini-Mental State Examination (MMSE) in four studies (2-5) and with instruments other than the MMSE in six studies (2,4,7-9,18). The outcome measure of depression was included in five studies (2-5,7), and in four studies each, researchers assessed activities of daily living (2-5); satisfaction with health care (7,11,12,16); and use of healthcare services (4,7,9,16). In two studies each, patient outcome measures included health-related quality of life (2,17); behavioural and psychological symptoms (2,4); quality of patient care (5,17); and patients' relationship with their caregiver (7,18). In one study each, researchers assessed patients' decision-making capabilities (5); comorbidity (4); wandering risk (5); embarrassment and isolation due to memory problems (7); administration of lab tests (5); use of cholinesterase inhibitors (17); referral to Alzheimer's Association or other organizations (5); and institutional placement (18).

### *Caregivers*

The most frequently measured outcomes for caregivers included depression, health, caregiver burden, and satisfaction with healthcare.

Researchers assessed caregivers for depression (9,15,18), health (4,9,17), caregiver burden (9,15,16), and satisfaction with healthcare (11,12,16) in three studies each. Social support and caregiver mastery were assessed in two studies (8,17), and patients' care specifically in two studies (4,5).

In one study each, caregivers were assessed for stress (4); anxiety and insomnia, social dysfunction, and somatic symptoms (18); health-related quality of life (17); relationship strain (with patient) (8); self-efficacy for managing dementia (9); knowledge about dementia (17); confidence (17); community services received and unmet need for behavioural management assistance (17), referrals to community resources (5), and receipt of educational materials (5).

### *Healthcare providers*

In order of frequency, the outcomes most commonly measured at the healthcare provider level included adherence to dementia care guidelines (5,16,17); knowledge (3,6,16); attitudes (6,16); confidence (3,16); satisfaction with patient/caregiver care (5,12), practices of diagnosis and referral (5), perceptions of care quality (6), number of assessments and diagnoses (16), and use of educational materials.

### *Services*

Formal service outcomes were evaluated in one study (2). In this particular study, researchers assessed six intervention goals, two of which included obtaining a low rate of refusal from referrals and increasing the number of new dementia cases seen each year.

## **Results**

Two of the 18 studies included in this review did not publish study results since the interventions either had not been conducted (16) or had not been evaluated (13). Four studies did not include formal outcome measures (1,10,13,14), however, three of the four studies (1,10,14) reported results based on qualitative assessments.

To examine the positive results associated with dementia care interventions, we summarize the results according to the same four categories used to examine the outcome measures: patients, caregivers, healthcare providers, and services.

### *Patients*

Researchers reported positive results for intervention patients (either in comparison to control patients or between baseline and follow-up) in eight of the 18 studies included in this review. Positive patient findings included decreased behavioural disturbance (2,4); less difficulty coping with memory problems (7); lower relationship strain with caregiver (7); improved quality of life (2); diminished decline in quality of life over time (17); improved quality of care (5,17); satisfaction with care (1,7,12); lower healthcare service use among patients (7); and nursing home admission rates equivalent to patients receiving usual care (vs. intervention) (18).

### *Caregivers*

Positive results for intervention caregivers (either in comparison to control caregivers or between baseline and follow-up) were indicated in nine of the 18 studies in this review. Positive caregiver outcomes associated with dementia care interventions consisted of lower stress (4); greater patient care satisfaction (4,5); satisfaction with care (1,10-12); lower rate of increase in depression over time (15); greater mastery (17); greater social support (17); lower unmet need for behavioural management assistance (17); and greater decrease in anxiety and insomnia (18).

### *Healthcare providers*

In six of this review's 18 studies, researchers reported positive results among healthcare providers. Positive findings referred to care satisfaction (1,5,12); greater satisfaction with patient care (5); knowledge improvement (3); greater confidence (3,12); greater quality of patient care (12); stronger guideline adherence (17); and fewer visits from patients with dementia in crisis (14).

### *Services*

Service outcomes were evaluated in one study (2). In this study, researchers found (in comparison to study goals), lower referral refusal rates, lower rate of inappropriate referrals, higher rate of referrals from minority ethnic groups, higher proportion of patients with mild impairment, and higher increase in rate of new dementia cases seen (2).

## **SUMMARY**

This review examined 18 studies that explored case/care management or collaborative care in relation to persons with dementia or Alzheimer's disease, within primary care settings.

The areas targeted for intervention in the studies included in this review fell into four categories: patient assessment, diagnosis, and patient/caregiver management; patient or caregiver support; patient or caregiver follow-up; and education/training. Patients were assessed or diagnosed as part of the intervention in 12 studies, and patient/caregiver management was

incorporated into the intervention in all 18 studies. Of those interventions that targeted patient or caregiver support, individual support (n=10) was more common than group support (n=5). Most studies included patient/caregiver follow-up as part of their interventions (n=10), the majority of which indicated that first follow-up occurred before the one-month point (n=6). Education and training, particularly for caregivers (n=7) and healthcare providers (n=5), were targeted in 11 studies. And although only four studies reported on interventions that incorporated web-based technology to support dementia care, the number of such studies will likely continue to grow.

Primary care providers (FPs/GPs and nurses) and specialists were integral to the interventions included in this review, with 13 studies involving FPs/GPs and nine studies involving nurses. In most of the studies, a care/case manager was also employed to enhance patient/caregiver care by performing a number of roles, including but not limited to administering assessments, co-ordinating care, facilitating communication, and providing patient/caregiver support.

Researchers used numerous outcome measures to determine the impact of their interventions. These measures fell into four categories: patients, caregivers, healthcare providers, and service outcomes. Among patients, the most common outcome measure was cognitive status (n=8), followed by measures of depression (n=5), activities of daily living (n=4), satisfaction with healthcare (n=4), and use of healthcare services (n=4). The most frequently measured outcomes for caregivers included depression (n=3), caregiver burden (n=3), health (n=3), and satisfaction with healthcare (n=3). In order of frequency, the outcomes most commonly measured at the healthcare provider level included adherence to dementia care guidelines (n=3), knowledge (n=3), attitudes (n=2), and confidence (n=2). Formal service outcomes were evaluated in one study.

Among the studies reporting positive findings associated with interventions, the findings fell into the four categories of patients, caregivers, healthcare providers, and services. First, positive findings regarding patient outcomes associated with dementia care interventions were reported in eight studies. These positive findings included decreased behavioural disturbance (n=2), less difficulty coping with memory problems (n=1), lower relationship strain with caregiver (n=1), improved quality of life (n=1), improved quality of care (n=2), satisfaction with care (n=3), and lower healthcare service use (n=1). Second, researchers reported positive findings regarding caregiver outcomes related to interventions in nine studies, regarding lower stress (n=1), greater mastery (n=1), greater social support (n=1), lower rate of increase in depression (n=1), greater decrease in anxiety and insomnia (n=1), greater satisfaction with patient care (n=2), and lower unmet need for behavioural management assistance (n=1). Third, positive findings pertaining to healthcare providers involved in interventions were reported in six studies, including care satisfaction (n=3), greater satisfaction with patient care (n=1), improvement in knowledge (n=1), greater confidence (n=2), greater quality of patient care (n=1), stronger guideline adherence (n=1), and fewer visits from patients with dementia in crisis (n=1). Lastly, one study reported positive findings with regard to services such as referral refusal rates, inappropriate referrals and rate of new dementia cases seen.

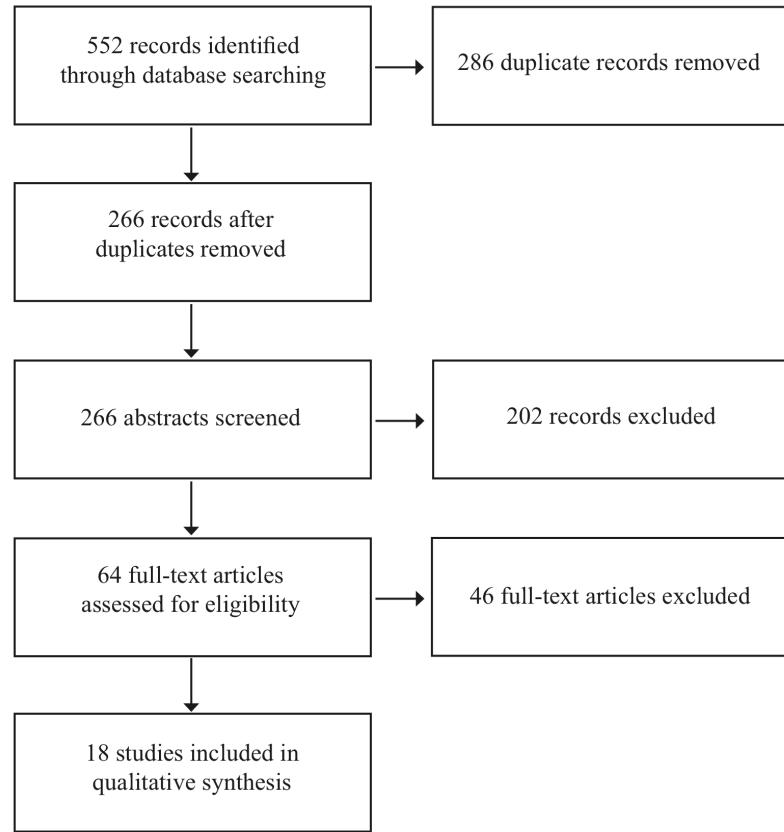


Figure 1. Flow diagram of selection of articles for systematic review.

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
1. Austrom et al. (2006) US	<p><b>Objectives</b> To “provide best practice dementia care in primary care clinics, using the most recent management guidelines in the USA for AD.” (Alzheimer’s Disease)</p> <p><b>Study design</b> 3340 patients of one urban primary care practice, aged 65 years and over, completed a 6-item screen for cognitive impairment as part of their regular visit; 227 completed the 18-item CSF’D screen; 127 were diagnosed with AD using the NINDS-ADRDA criteria; and 55 patients were randomized to the intervention group.</p> <p><b>Participants:</b></p> <ul style="list-style-type: none"> <li>- 55 patients aged 65 years and over (71% women, average age 76 years, 58% African-American)</li> <li>- 55 caregivers (78% women, average age 54 years)</li> </ul>	<p>PREVENT Study (Providing Resources Early to Vulnerable Elders Needing Treatment for Memory Loss): The consensus team agreed on pharmacotherapy treatment recommendations, which were presented by the GAPN. All patients and their caregivers also received “advice on communication skills; caregiver coping skills; legal and financial advice; exercise guidelines with a guidebook and videotape; and a ‘Caregiver Guide.’” Monthly support group meetings were offered to caregivers and PWD. Follow-up by telephone to the caregiver by the GAPN occurred at 1-2 weeks, 1 month in-person, and in-person and by phone at 4-week or 12-week intervals up to 12 months. The consensus team met at 2-month follow-up.</p>	<p>The consensus team included a geriatric advanced practice nurse (GAPN), social psychologist, geriatrician, and geriatric psychiatrist. The GAPN was responsible for co-ordinating care, writing orders, implementing the intervention, and follow-up. Twenty-six (26) primary care providers (PCPs) participated in the study.</p>	<p>Outcome results were not reported, as the “results of the intervention are not yet available”.</p>	<p>The care model was accepted by patients, caregivers, and PCPs. Caregiver-directed interventions were well accepted. The GAPN and the PCPs met more than one time for 56% of patients. PCPs appreciated the extra resources that the GAPN offered to patients. The GAPN had an average of 11 contacts with each patient and caregiver, mostly face-to-face. The monthly support groups were attended regularly by approximately half of the patients and caregivers.</p>

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2. Banerjee et al. (2007) UK	<p><b>Objectives</b> To provide “early identification and engagement with people with dementia and their carers” and “a comprehensive early assessment, diagnostic and treatment service for people with dementia and their carers.”</p> <p><b>Study design</b> 290 people were referred to the urban Croydon Memory Service (CMS) for assessment, 247 were assessed at baseline, and 141 of those patients participated in 6-month follow-up (blind to initial assessment). Of the 247 patients assessed at baseline, 77% had mild, minimal, or no cognitive impairment (MMSE scores of 19-30) and 22% had moderate to severe cognitive impairment (MMSE scores of 0-18).</p>	<p>CMS Model (Croydon Memory Service) for early dementia assessment and care in dementia: Patients diagnosed with dementia were offered individual and group support with their caregivers, if appropriate, and all were offered individual care. The main goal of the CMS was to improve quality of life for patients with dementia. Follow-up occurred at 6 months.</p> <p>Data were collected on an 18-month cohort of patients consecutively referred. The duration of the study was 18 months.</p>	<p>The team was intended to be ‘generic’, and included five members (not described). Any team member could perform the initial assessment. The whole team developed the management plan. Assessment and care took place in patients’ homes.</p>	<p><i>Patient outcomes</i> Mini-Mental State Examination (MMSE)</p> <p>Cambridge Cognition Examination (CAMCOG)</p> <p>Neuropsychiatric Inventory (NPI)</p> <p>Disease-specific health related quality of life (DEMQOL and DEMQOL-Proxy)</p> <p>Bristol Activities of Daily Living Scale (BADL)</p> <p>Geriatric Depression Scale (GDS)</p>	<p><i>Patient outcomes</i> At 6-month follow-up, patients’ quality of life had significantly improved, as rated by DEMQOL and DEMQOL-proxy; and behavioural disturbance had significantly decreased, as rated by NPI.</p> <p><i>Service outcomes</i> The refusal rate was 5%. The “inappropriate” referral rate was 11%. The team received 44 referrals from non-white European ethnic groups. Of those patients referred, 77% had mild to minimal impairment. The number of new dementia cases seen within a 1-year period increased by 63% (from 215 people diagnosed with dementia to 416 people diagnosed).</p> <p><i>Service outcomes</i> The authors identified six goals: to have a low rate of refusal from referrals of less than 10%, have a low rate of “inappropriate” referrals of less than 20%, work for minority and majority groups, focus on mild cases to facilitate early intervention with 60% of patients mildly impaired, engage with people with young-onset dementia with 10% under age 65, and increase the number of new dementia cases seen each year by 50%.</p>

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3. Boongird et al. (2011) Thailand	<p><b>Objectives</b> To “uncover geriatric problems and syndromes in multiple domains, including medical, functional, social and psychological aspects” and to “evaluate the impact of a geriatric assessment clinic on practice management from the perspective of the family practitioner.”</p> <p><b>Study design</b> 177 patients were evaluated by the geriatric assessment clinic team at an urban family medicine outpatient clinic (number of patients assessed for eligibility was not reported).</p> <p><b>Participants</b> <i>Baseline</i> - 177 patients at baseline (67% women, average age 75 years) <i>Annual or bi-annual follow-up</i> - 95 patients (gender and age not reported) 18-month follow-up: - survey of 43 family physicians (81% response rate)</p>	<p>Geriatric assessment clinic: Patients were managed and followed by the team and home healthcare providers for the syndromes of dementia, depression, gait problems, multiple falls, polypharmacy, and elderly mistreatment. The team gave patients’ family physicians written care plans and recommendations to manage these syndromes. Special care services for common geriatric conditions were also suggested by the team, such as an eye clinic and dental clinic. The team provided bi-annual and annual follow-up.</p> <p>Data were collected by family physician survey 18 months after the clinic had been established. The duration of the study was 18 months.</p>	<p>The team included two internists, one geriatric medicine board-certified family physician, two nurses, two pharmacists, two social workers, and one clinical psychologist. Physicians took the patient’s history and performed a physical exam. Nurses collected demographic data, identified caregivers, evaluated functional status, measured visual acuity, interviewed and reviewed medical records of patients who had annual colorectal cancer screening or annual mammogram, osteoporosis screening, and influenza vaccine, and recorded ADL and IADL. Social workers reviewed family genealogy and assessed for abuse, family conflict, and caregiver burden. Pharmacists evaluated non-prescription and prescription drugs. Clinical psychologists screened for cognitive and psychiatric problems.</p>	<p><b>Patient outcomes</b> Barthel Index to assess Activities of Daily Living (ADL) Chula Index to assess Instrumental Activities of Daily Living (IADL) Thai Mini-Mental State Examination (Thai MMSE) Geriatric Depression Scale (GDS-15)</p> <p><b>FP outcomes</b> Family physicians reported geriatric knowledge gain in the topics of geriatric syndrome, drug use, holistic approaches, and geriatric prevention. Attitudes toward the elderly also improved, as family physicians reported greater confidence in elderly care, multidisciplinary care, and benefits for patients and caregivers. Family physicians indicated that the geriatric assessment clinic enhanced the primary care system and continuity care system.</p>	<p><b>Patient outcomes</b> These measures were administered at baseline only; the authors did not report follow-up results.</p>

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4. Callahan et al. (2006) US	<p><b>Objectives</b> To “test the effectiveness of a collaborative care model to improve the quality of care for patients with Alzheimer disease.”</p> <p><b>Study design</b> Randomized controlled trial: Patients from two large urban primary care practices were recruited if they screened positive for cognitive impairment or had a medical record diagnosis of dementia (number of patients recruited was not reported). 464 patients completed a diagnostic assessment that included a neuropsychological battery (from the Consortium to Establish a Registry for Alzheimer Disease), caregiver interview (if the patient had a caregiver), and a neurological and cardiovascular physical exam. A consensus diagnosis panel determined that 206 patients met DSM-III criteria for AD and were eligible; 153 patients participated.</p> <p><b>Participants</b> <b>Intervention</b>            - 84 patients (46% women, average age 77 years)            - 84 caregivers (83% women, average age 60 years)            - 37 primary care physicians  <b>Augmented usual care patients</b>            - 69 patients (39% women, average age 78 years)            - 69 caregivers (96% women, average age 62 years)            - 37 primary care physicians         </p>	<p>The collaborative care team included a family physician and geriatric nurse practitioner (care manager). The care manager provided the diagnosis, written materials, and in-person counselling to intervention and augmented usual care patients and caregivers in a 40-90 initial meeting with recruited patients. Augmented care patients received the usual care from their family physician. For the intervention group, the care manager recommended treatment with cholinesterase inhibitors and a minimum intervention of communication skills, caregiver coping, legal and financial advice, patient exercise with guidebook and video, and a caregiver guide from the Alzheimer’s Association. Care managers saw patients and caregivers two times/month and then one time/month for 12 months. Using scores on the Memory and Behaviour Problems Checklist completed by caregivers at each meeting with the care manager, care managers offered caregivers 8 different protocols for non-pharmacotherapy interventions (see outcome measures). If these protocols did not resolve the problems, care managers collaborated with family physicians to offer drug therapy.</p> <p>Data were collected on patient and caregiver outcomes at baseline, 6, 12, and 18 months. The duration of the intervention was 12 months.</p>	<p>The collaborative care team included a primary care physician and a geriatric nurse practitioner (care manager). The consensus diagnosis panel/support team included a psychologist, neuropsychologist, geriatrician, and geriatric psychiatrist. The care manager communicated the diagnosis to patients and caregivers and managed patients using a longitudinal tracking system. The support team and care manager met weekly to review the care of new and ongoing patients. A social psychologist offered voluntary support sessions for caregivers, simultaneously with exercise sessions for patients offered by a health psychologist and the care manager.</p>	<p><i>Patient outcomes</i> Memory and Behaviour Problems Checklist Neuropsychiatric Inventory (NPI) Activities of Daily Living Health care resource use</p> <p><i>Caregiver outcomes</i> Cornell Scale for Depression in Dementia Mini-Mental State Examination Chronic disease score (to measure medical comorbidity)</p> <p><i>Process of care outcomes</i> Caregiver Stress (NPI) Patient Health Questionnaire-9 Caregiver satisfaction with patient's care</p>	<p><i>Patient outcomes</i> Intervention patients had significantly lower NPI scores (fewer behavioural symptoms) than augmented care patients. Health care resource use during the 12-month study period was significantly lower among augmented care than intervention patients, with significantly fewer nurse and physician visits. Hospitalization rates, hospital days, and nursing home placement rates were not significantly different between the two groups.</p> <p><i>Caregiver outcomes</i> Caregivers of intervention patients had significantly lower NPI scores (fewer symptoms of stress) and significantly lower Patient Health Questionnaire-9 scores (lower stress) than augmented care caregivers. Caregivers of intervention patients were significantly more satisfied with the patient's primary care than caregivers of augmented care patients.</p> <p><i>Process of care outcomes</i> Frequency of initiation for any one of the 8 protocols (personal care, repetitive behaviour, mobility, sleep disturbances, depression, agitation or aggression delusions, hallucinations, and caregiver's health).</p>

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5. Cherry et al. (2004) US	<p><b>Objectives</b> To “improve quality of dementia care in a Kaiser Permanente service area through rigorous dissemination of practice guidelines and social worker support for physicians and patients.”</p> <p>The “goal of the Dementia Care Project was to improve the quality of care for people with dementia while increasing provider and consumer satisfaction.”</p> <p><b>Study design</b> Longitudinal preintervention/postintervention design. Patients within Kaiser Permanente’s Metropolitan Los Angeles Service area were referred by their primary care physician to the study (number of patients referred was not reported), and were eligible if they had a guideline-based diagnosis of dementia, did not live in an institution, and had a non-paid caregiver. 83 patients enrolled in the study.</p>	<p>Dementia Care Project to improve care quality for people with dementia and provider and consumer satisfaction: As part of the project, the California Alzheimer’s Disease Management Guideline was developed and disseminated as a laminated pocketbook, along with forms and tests for mental status, to all primary care physicians in the Service area. Physicians were also offered in-service training. Physicians participated in the intervention by following the California Alzheimer’s Disease Management Guideline, developed for this study.</p>	<p>The study included primary care physicians at 2 large medical centres and many satellite clinics within the Kaiser Permanente service area, plus 2 social work care managers. After the initial regular patient visit, primary care physicians referred patients to the study. Patients were assessed with a Mini-Mental Status Examination (MMSE) by their physician, neurologist, or care manager. The care manager supported physicians by administering mental status exams to patients, providing family follow-up, offering home visits, behaviour management, and arranging management of co-morbid conditions by physicians. The care managers connected caregivers with Kaiser Permanente and community resources, support groups, education, and continuous care management.</p>	<p><b>Patient outcomes</b> Folstein Mini-Mental Status Examination (MMSE) Lab tests (syphilis, thyroid-stimulating hormone, complete blood count, and blood chemistries). Referral to the Alzheimer’s Association and Safe Return Program significantly increased postintervention, with most of the referrals made by the care managers. Assessment of daily living activities were significantly more likely to be documented postintervention, as were decision-making capacity, depression, and wandering potential. Most of the documentation of daily living activities and wandering risk was made by care managers, while most of the documentation of depression was made by primary care physicians.</p> <p><b>Caregiver outcomes</b> Satisfaction with Kaiser Permanente dementia services Receipt of educational materials Referrals to community resources</p>	<p><b>Patient outcomes</b> The MMSE was significantly more likely to be administered postintervention than preintervention. Referral of patients to the Alzheimer’s Association and Safe Return Program significantly increased postintervention, with most of the referrals made by the care managers. Assessment of daily living activities were significantly more likely to be documented postintervention, as were decision-making capacity, depression, and wandering potential. Most of the documentation of daily living activities and wandering risk was made by care managers, while most of the documentation of depression was made by primary care physicians.</p> <p><b>Caregiver outcomes</b> Caregivers were significantly more likely to be satisfied with dementia services postintervention. Caregivers were significantly more likely to receive educational materials and referrals to community resources postintervention.</p> <p><b>Primary care physician outcomes</b> Diagnostic practices Referral behaviours Satisfaction with patient and caregiver care Adherence to dementia guidelines</p> <p><b>Primary care physician outcomes</b> Satisfaction with dementia services significantly increased postintervention. Physicians were significantly more likely to order lab tests to diagnose dementia postintervention.</p>

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6. Chodosh et al. (2006) US	<p><b>Objectives</b> To “evaluate the effect of a multicomponent dementia care management program on primary care provider knowledge, attitudes, and perception of quality of dementia care.”</p> <p><b>Study design</b> Primary care providers (PCPs) at 16 clinics that participated in the ACCESS study (see Vickrey et al., 2006) were invited to participate in the Care Management Program Study. Eligible PCPs included internists, family physicians, nurse practitioners, and physician’s assistants. 232 PCPs were eligible and 166 PCPs participated in the study (72% response rate).</p>	<p>The Care Management Program study was one component of the ACCESS study, the goal of which was to improve dementia care among patients aged 65 and older (see Vickrey et al., 2006 for a description of the ACCESS study). The ACCESS study involved 8 intervention and 8 usual care clinics. Intervention PCPs and care managers used web-based software to communicate about patients, refer to community agencies, plan collaborative care with caregivers, support caregiver self-management, and maintain follow-up. Education modules were also offered to PCPs at 8 intervention clinics.</p> <p>Intervention and usual care PCPs were surveyed to compare PCP outcomes.</p>	<p>The Care Management Program study involved PCPs at 16 clinics participating in the ACCESS study, including 8 intervention clinics and 8 usual care clinics. The 8 intervention clinics also included care managers. PCPs included internists, family physicians, nurse practitioners, and physician’s assistants. Care managers shared communications with PCPs concerning patient assessments with potential problems flagged, and facilitated patient follow-up by PCPs in cases of depression, behaviour or function changes to PCPs, decision-making capacity assessments, and caregiver concerns.</p>	<p><b>PCP outcomes</b> Knowledge (4 measures) Attitudes (3 measures) Perceptions of quality of dementia care (3 measures)</p>	<p><b>PCP outcomes</b> Intervention PCPs were significantly more knowledgeable than usual care PCPs regarding capacity assessment for decision-making. No other knowledge differences were observed.</p> <p>Intervention PCPs were significantly more likely than usual care PCPs to agree that older patients with dementia are difficult to manage in primary care. No other attitude differences were observed. Perceptions of dementia care quality did not significantly differ between intervention and usual care PCPs.</p>

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7. Clark et al. (2004) US	<p><b>Objectives</b></p> <p>The 'primary study hypothesis posits that patients who are offered care consultation will have decreased utilization of managed health care services and improved psychosocial abilities to deal with memory problems over the 12-month study period. The secondary modifying-effects hypothesis posits that benefits of care consultation will be greater for patients with more severe memory impairment.'</p> <p><b>Study design</b></p> <p>Study patients were Kaiser Permanent patients, aged 55 years and older, whose medical records indicated a diagnosis of dementia or a symptom of memory loss. 525 patients were eligible for the study, 233 patients agreed to be contacted by the study team, and 210 patients agreed to participate in the study. 121 patients completed an in-person baseline interview (70% of the 210 patients were too impaired and 30% refused.) 89 of the 121 patients completed an in-person 1 year follow-up interview.</p> <p><b>Participants</b></p> <p><b>Baseline</b></p> <ul style="list-style-type: none"> <li>- 121 intervention and control patients (gender and age not reported)</li> </ul> <p><b>1-year follow-up</b></p> <ul style="list-style-type: none"> <li>- 89 intervention and control patients (gender and age not reported)</li> </ul>	<p>The Cleveland Alzheimer's Managed Care Demonstration was a telephone intervention to help patients and caregivers identify family, health system, and community resources. All patients enrolled in the study completed a baseline interview, and 60% of patients were then randomized to the intervention group and 40% to the control group. Intervention patients were contacted by telephone by a care consultant within 5 days of the baseline interview. Control patients were not contacted, but could initiate contact with the Association just like any other community member. Control patients did not receive services from care consultants, but could receive Association services that included education and training, support groups, and respite care. Intervention patients completed a structured initial assessment to create an individual care plan with specific tasks for patients, caregivers, and Association staff, a time frame for completing tasks, and a time frame for follow-up. Intervention patients were followed up every 2 weeks, then depending on need, monthly, then every 3 months. Some patients and caregivers received more frequent contact, depending on need.</p>	<p>Patients in the intervention and control groups received services from three social workers (care consultants) employed by the Cleveland Area Alzheimer's Association, in addition to services from Association staff and volunteers. Care consultants conducted structured initial assessments, identified problems, and used resources at the family and community levels to address the problems.</p>	<p><b>Patient outcomes</b></p> <p>Blessed Orientation-Memory-Concentration Test (Blessed Test)</p> <p>Health care use</p> <p>Satisfaction with health care (Kaiser) services</p> <p>Depression (CES-D)</p> <p>Relationship Strain</p> <p>Embarrassment and isolation due to memory problems</p> <p>Difficulty coping with memory problems</p>	<p><b>Patient outcomes</b></p> <p>Intervention patients with more severe memory problems, compared with similar control patients, had significantly fewer hospital admissions, emergency department visits, and physician visits. Intervention patients with more severe memory problems, compared with similar control patients, were significantly more satisfied with their health care services. Relationship strain among intervention patients with more severe memory problems was significantly more likely to decrease than among control patients with a similar level of memory problems. Embarrassment and isolation due to memory problems, and difficulty coping with memory problems, were significantly lower among intervention than control patients.</p>

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8. Connor et al. (2008) US	<p><b>Objectives</b> To “identify specific care management activities within a dementia care management intervention that are associated with 18-month change in caregiver mastery and relationship strain.”</p> <p><b>Study design</b> Randomized controlled trial: 18 urban clinics were recruited to the study. Patients with a diagnosis of dementia and informal caregiver were recruited, with patients from 9 of these clinics receiving intervention care and patients from 9 of the clinics receiving usual care. 408 patient/caregiver pairs from the 18 participating clinics enrolled in the study, 238 of these pairs were randomly assigned to the intervention, 181 pairs received dementia care management services, and 165 of the 238 pairs participated in the 18-month follow-up.</p> <p><b>Participants</b> <i>Baseline</i> - 238 intervention patients (54% women, average age 80 years) - 238 intervention caregivers (69% women, average age 66 years) <i>18-month follow-up</i> - 165 patients (gender and age not reported) - 165 caregivers (gender and age not reported)</p>	<p>The ACCESS Study (Alzheimer’s Disease Coordinated Care for San Diego Seniors) to identify care management activities related to improvement in caregiver mastery and relationship strain (see Vickrey et al., 2006 for a description of the ACCESS study): Three healthcare organizations and three social service agencies collaborated on the ACCESS program. Care management protocols followed evidence-based guidelines. Patients in the intervention group received structured assessments in their home by care managers, who then developed a care plan and care management activities to be implemented by care managers at community agencies. Caregivers participated in developing care plans and received copies and updates of the plans. Care managers communicated with one another about patients and caregivers, coordinated interventions, and provided continuity of care by following up referrals to healthcare organizations and community agencies. Communication, assessment, care planning, follow-up, and referrals were supported by a web-based care management system.</p>	<p>The ACCESS Study (Alzheimer’s Disease Coordinated Care for San Diego Seniors) care manager program included nurse care managers at healthcare organizations and social work care managers at social service agencies. The care managers collaborated to identify patient and caregiver needs, plan interventions, and follow up referrals to healthcare organizations and community agencies. Decision support was provided to care managers in the healthcare organizations and social service agencies from physician champions, who also promoted the ACCESS program to their colleagues at the intervention clinics.</p>	<p><i>Patient outcomes</i> Blessed-Roth Dementia Severity Scale California Dementia Behaviour Questionnaire (CDBQ)</p> <p><i>Caregiver outcomes</i> Social support Caregiver mastery and relationship strain (Margaret Blenkner Research Centre Caregiver Strain Instrument)</p>	<p>Four care management domains were identified from 45 variables that represented “types” of care management activities: behavioural management, clinical strategies and caregiver support, community agency service, and safety.</p> <p><i>Patient outcomes</i> Behaviour composite score was not associated with caregiver mastery (authors did not report other patient outcomes).</p> <p><i>Caregiver outcomes</i> Caregiver mastery improvement between baseline and 18-months was significantly associated with the care management activity of “care manager assessment of the home environment” and caregiver mastery decline was significantly associated with the care management activity of “caregiver to explore community options”. Social support was not significantly associated with mastery.</p> <p>18-month change in relationship strain was not significantly associated with any variable.</p>

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9. Fortinsky et al. (2009) US	<p><b>Objectives</b> To evaluate the “efficacy of an individualized dementia care consultation intervention for family caregivers of patients with diagnosed dementia living in the community.”</p> <p><b>Study design</b> Randomized controlled trial: 41 clinics in cities, small cities, and towns were recruited to the study. Primary care physicians referred caregivers of dementia patients to the study. Eligible patients had a diagnosis of dementia, resided in the community, had at least one family caregiver, were ambulatory, and received regular medical care from the referring physician. The number of patients and caregivers referred to the study by primary care physicians was not reported. 178 caregivers contacted the study team after they were referred by their primary care physician. 160 caregivers were eligible and 84 caregivers participated at baseline.</p> <p><b>Participants</b> <b>Baseline</b> - 54 intervention group caregivers (63% women, average age 65 years) - 30 control group caregivers (80% women, average age 58 years) <b>12-month follow-up</b> - 75 caregivers (authors did not report the number of caregivers in each group)</p>	The dementia care consultation was an intervention to increase caregivers' self-efficacy in symptom management and service access, and to lower nursing home admission rates among dementia patients. All caregivers of patients in the intervention and usual care groups were interviewed at baseline and subsequently received a package of education and resource materials. Intervention group caregivers received care consultation and dementia education and community resource materials. Usual group caregivers received the same education and resource materials but did not receive care consultation and were not contacted again by study personnel until 12-month follow-up. Intervention caregivers received a standardized assessment and monthly contact from a care consultant. Monthly care plans with action steps were developed by caregivers and the care consultant cooperatively to identify concerns about patients and caregiver issues. Care plans also included information concerning the disease process, legal and financial planning, family support groups, educational programs offered by the Alzheimer's Association and other community resources, and services for adult day care and respite care.	<p>This study involved individualized dementia care consultation provided by a professionally trained dementia care consultant at one state chapter of the Alzheimer's Association. The care consultant had an initial in-person meeting and final 12-month meeting with intervention group caregivers in their home or the patient's home. The care consultant used a standardized assessment process to develop a care plan and action steps with caregivers each month for 12 months. The care consultant fixed the care plan to each patient's physician, so that physicians could review and reinforce the care plans with their patients and caregivers. The care consultant role was filled by one person at a time, including a speech and language therapist for a number of months, followed by a clinical social worker, followed by a licensed clinical social worker.</p>	<p><b>Patient outcomes</b> Nursing home admission rates during the 12-month study period were not significantly different for patients in the intervention and control groups.</p> <p><b>Caregiver outcomes</b> Outcomes for intervention caregivers were not significantly different than outcomes for control caregivers at 12-month follow-up.</p> <p><b>Intervention group</b> caregivers appreciated monthly care consultation and monitoring, but wanted to have more individualized care tailored to the stage of dementia of their loved one and more practical information about making decisions regarding care.</p> <p><b>Intervention group</b> caregivers also were dissatisfied with the “personality differences” between the three different care consultants, only one of which filled the care consultant role at a given time.</p>	

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10. Gladman et al. (2007) UK	<p><b>Objectives</b> To evaluate “a specialist community-based dementia service to establish whether high quality care was being delivered and the conditions for doing so.”</p> <p><b>Study design</b> Descriptive study: The Nottingham Daisy Chain Service was an urban dementia support service that had already been established when a Service co-ordinator asked the research team to conduct an external independent investigation.</p> <p><b>Participants</b> The Nottingham Daisy Chain accepted 120 new referrals during 2002 and 2003. Patients’ average age was 83 years and 83% were women. The Service closed 24% of cases within 6 weeks and 57% within 6 months.</p>	<p>Nottingham Daisy Chain dementia support service took a “rehabilitative approach” to dementia care. The purpose of the intervention was to help the person with dementia to live as normal a life as possible with tailored support. The structure of patients’ days was assessed over 12 weeks by an occupational therapist. A care plan was established during this 12-week period, and special community care workers provided care one or more times daily. The care workers were guided by a shared autonomy-respecting ethos.</p>	<p>The Nottingham Daisy Chain Assessment team included an occupational therapist, community psychiatric nurse, community care officer, and a team of specially trained community care workers.</p>	<p>Formal outcome measures were not reported.</p>	<p>Caregivers noted that good care was care that patients accepted and enjoyed. Caregivers indicated that care workers were kind, understanding, and communicated well (e.g., patients’ homes contained a “communication book” for staff and caregivers). Caregivers appreciated personalized and individualized care, in comparison to standardized care provided in fixed time periods by the dementia program previously in place.</p> <p>General practitioners indicated that patients receiving the Service were less likely to “trouble” them than patients who received services from the dementia program previously in place.</p> <p>Negative comments suggested that the Service prolonged the time that patients remained in their homes, and (inappropriately) delayed institutionalization.</p>

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11. Greening et al. (2009) UK	<p><b>Objectives</b> To “improve the service (of primary dementia care) to patients and families, and to strengthen primary care competence in the recognition and management of memory disorders.”</p> <p><b>Study design</b> Descriptive study: The Gnosall Memory Clinic was a service for patients with memory difficulties within an existing primary care practice. Patients were referred to the Clinic by their general practitioner (GP) or other clinician within the primary care practice via the community mental health team or the consultant in old-age psychiatry.</p> <p><b>Participants</b> - 41 patients seen in a 23-month period (54% women, 50% of women aged 85 years and older)</p>	<p>The Gnosall Memory Clinic to improve patient and family services, and to improve recognition and management of memory disorders in primary care: The Gnosall Memory Clinic was established within a primary care practice. Patients were referred to the Clinic by their GP or other clinician with the primary care practice. The consultant in old-age psychiatry prepared a patient assessment based on a clinic consultation protocol. This assessment was reviewed by the health visitor, clarified by patient and caregiver interviews, and shared with patients and caregivers. The Clinic provided on-going support regarding skills and advice to general practitioners.</p>	<p>The Gnosall Memory Clinic included eight general practitioners (GPs), two health visitors (practice liaison clinicians), four district nurses, two practice nurse, a physiotherapist, and a consultant in old-age psychiatry. The psychiatry consultant provided one clinical work session in the Clinic each month, and otherwise provides consultation services by phone or email.</p>	<p><i>Patient outcomes</i> Satisfaction with Memory Clinic</p> <p><i>Caregiver outcomes</i> Satisfaction with Memory Clinic</p>	<p><i>Patient and caregiver outcomes</i> The authors did not report significant results, however they noted that patients and caregivers were pleased that the facility was in place and saved them from travelling to a hospital for such as service.</p>

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12. Lee et al. (2010) Canada	<p><b>Objectives</b> To “provide timely access to comprehensive assessment and care and to improve referring physicians’ knowledge of the management of dementia through collaborative care and practice-based mentorship.”</p> <p><b>Study design</b> The Primary Care-Based Memory Clinic was a family-physician (FP) led memory clinic within an existing Family Health Team (FHT) practice. The FHT included physicians, nurses, social workers, pharmacists, and other healthcare providers. Patients were referred to the Memory Clinic by an FP within the FHT. During a 9-month period (2008 to 2009), 40 patients and 40 caregivers were seen in the Memory Clinic, and 24 patients and 17 caregivers participated in this study.</p>	<p>The Primary Care-Based Memory Clinic to provide access to comprehensive assessment and improve FPs’ confidence and knowledge in managing cognitive impairment. The Memory Clinic offered services 1 or 2 clinic days/months, and conducted four assessments and two follow-ups each clinic day. Once a patient was referred to the Memory Clinic by an FHT FP, the patient/caregiver was contacted with a time for a Memory Clinic appointment and mailed a package of forms to complete for the appointment. The patient was assessed by the Memory Clinic team, and the patient and caregiver met with the team to review the assessment and to develop a management plan. The lead physician sent the patient assessment and management plan to the referring FP. Follow-up was provided on an individual basis in cooperation with the patient’s FP, ranging from 3 months to 1 year.</p> <p><b>Participants</b></p> <ul style="list-style-type: none"> <li>- 24 patients (gender and age not reported)</li> <li>- 17 caregivers (gender and age not reported)</li> <li>- 8 physicians (gender and age not reported)</li> </ul>	<p>The Memory Clinic included one family physician lead, two registered nurses, a social worker, a pharmacist, and a receptionist. A geriatrician provided consultation support by phone or email. The registered nurses were responsible for reviewing the patient information forms completed by caregivers, obtaining further patient history, and administering cognitive assessments (MMSE and/or MoCA, Trails A and B, CLOX, animal list generation, and other executive function tests as necessary).</p> <p>The social worker was responsible for assessing for depression, administering Frontal-Behavioural Inventory as necessary, assessing caregiver burden, and gauging need for home safety assessment. The pharmacist was responsible for review medication and assessing for medication non-adherence and possible adverse drug events.</p>	<p><i>Patient outcomes</i> Satisfaction with Memory Clinic</p> <p><i>Caregiver outcomes</i> Satisfaction with Memory Clinic</p> <p><i>FP outcomes</i> Satisfaction with Memory Clinic</p>	<p><i>Patient and caregiver outcomes</i> Patients and caregivers were very satisfied with the Memory Clinic. Most patients and caregivers indicated that they better understood their symptoms and conditions and would recommend the Clinic to others in need of such services.</p> <p><i>FP outcomes</i> FPs were very satisfied with the Clinic with respect to assessment, diagnosis, and treatment recommendations. More than half of FPs indicated that since participating in the Memory Clinic, their confidence had improved in assessing and managing cognitive impairment, and in speaking with patients and families. Most FPs also reported improvements in their quality of care to patients with cognitive impairment.</p>

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
13. McAiney (2008) Canada	<p><b>Objectives</b> To “support persons with Alzheimer’s and related diseases after the diagnosis is made and to link them with support services earlier in the disease course.”</p> <p><b>Study design</b> Descriptive study: The First Link program was a service for patients with dementia and their caregivers, as well as for primary care physicians and other healthcare professionals. Patients with physician’s diagnosis of dementia were contacted by First Link coordinators and given information regarding dementia and community services and education.</p> <p>Future evaluation will be based on a mixed method, prospective cohort design with data from First Link referrals and caregiver contact, as well as data collected from caregivers, healthcare providers, stakeholders, and clients.</p> <p><b>Participants</b> Future evaluation will include First Link clients, people with dementia, referring healthcare providers, and persons from the demonstration sites.</p>	<p>The First Link program to provide early education and support to people with Alzheimer’s and related diseases and their caregivers, was established as a partnership between the Alzheimer Society of Ottawa and the Champlain Dementia Network. The First Link program was similar to the Chronic Disease Prevention and Management Model (CDPM) in that it promoted self-management and encouraged collaboration between community organizations and the healthcare sector. When patients were diagnosed with dementia by their physician, the physician requested permission to share their contact information and the First Link coordinator made the initial patient/caregiver contact. The First Link coordinator provided information regarding dementia and community services and education. Long term support to patients/caregivers was provided by staff from the Alzheimer Society other than First Link coordinators. The Alzheimer Society offered education sessions to healthcare providers and caregivers directly, or indirectly through community resources.</p>	<p>The First Link program included First Link coordinators from the Alzheimer Society. First Link coordinators liaised with health care professionals such as family physicians and community service providers; improved management of non-medical issues by encouraging connections to community services; improved health care professionals’ understanding of dementia assessment, management, and community resources; and improved understanding of community resources among people with dementia and caregivers.</p>	<p>Formal outcome measures were not reported.</p>	<p>Results have not yet been reported.</p>

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
J. G. McNally et al. (1998) UK	<p><b>Objectives</b> To facilitate “early identification by primary healthcare staff, and earlier referrals to social services and specialist health provision.”</p> <p><b>Study design</b> Descriptive study: This project had already been established for two years before an evaluation was commissioned.</p> <p><b>Participants</b> 52 patients were referred to the Service in its first 2 years. 31 patients were regularly contacted by the social worker during this period.</p>	<p>A social worker accepted referrals of patients with dementia from GPs in one large group practice (approx. 13,000 practice population) and one small sole practice (approx. 2,000 practice population).</p> <p><b>Study design</b> Data were collected from 10 caregivers by individual interview, and from all other participants by group interview (2 GPs, 4 practice nurses, 3 social work team staff, 1 social services home care coordinator, a consultant in old age psychiatry, the project social worker, and the multidisciplinary team for elderly people with mental health problems). The duration of the intervention was three years.</p>	<p>A social worker collaborated with primary care teams to provide care management to patients with dementia referred by their general practitioner (GP). The social worker provided assessment and care planning, support, and liaison between primary care and specialist services. The social worker and consultant in old age psychiatry shared information, and conducted joint reviews and visits. A multidisciplinary team met twice a month, including the social worker, consultant in old age psychiatry, other social workers with active cases, community psychiatric nurses, and an occupational therapist.</p>	<p>Formal outcome measures were not reported.</p>	<p>GPs indicated that they saw fewer dementia patients in crisis. All healthcare professionals agreed that referrals of dementia patients in crisis had diminished and nursing home admissions had been delayed. All healthcare professionals agreed that the service increased specific use of home care and day care, increased use of caregivers, and decreased use of nursing homes.</p> <p>According to caregivers interviewed, the number of patients with dementia receiving health or social services increased from 1 out of 10 prior to establishment of this service to 8 out of 10.</p>

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
15. Newcomer et al. (1999) US	<p><b>Objectives</b> To determine whether “improved access to community-based care reduced(d) perceived burden and reported levels of depression among primary caregivers of people with dementia.”</p> <p><b>Study design</b> 8,138 individuals directly applied to the Medicare Alzheimer’s Disease Demonstration Evaluation (MADDE), and all of the applicants received a baseline assessment. Of these individuals, 5,307 were eligible to participate in the study, and 1,910 completed a 3-year follow-up. 2,732 caregivers were randomized to the intervention group, and 2,576 to the control group.</p> <p><b>Participants</b> <i>Baseline</i> - 2,731 intervention patients (72% women, average age 78 years) - 2,731 intervention caregivers (59% women, average age 63 years) <i>Follow-up</i> Authors did not report the demographic characteristics of the follow-up samples.</p>	<p>The Medicare Alzheimer’s Disease Demonstration Evaluation (MADDE) for dementia victims and their caregivers. All caregivers who participated at baseline were randomly assigned to either the intervention to receive case management and service coverage, or to the control group to receive usual care. All caregivers in the intervention group had the opportunity to access education and training regarding Alzheimer’s disease and related issues, via interactions with case managers or by participating in caregiver support groups. Caregivers also received information about community services and help with coordinating services and assistance, from case managers. Caregivers also received support services in the form of counselling services, transportation to education and support opportunities, and case management services for themselves and patients.</p>	<p>Case managers with The Medicare Alzheimer’s Disease Demonstration Evaluation (MADDE) were responsible for providing information, service assistance, and quality monitoring. The role of case managers was to provide information to caregivers regarding community services, help caregivers to choose service packages for patients, coordinate formal caregiving assistance, and monitor (demonstration project) service quality.</p>	<p><b>Caregiver outcomes</b> Caregiver burden scores between baseline and 3 year follow-up tended to decrease, however the difference in the average change in burden score was not significantly different between the intervention and control group. Caregiver depression scores between baseline and 3 year follow-up tended to increase, with a significantly lower rate of increase (although small) among the intervention than control group.</p>	

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
16. Perry et al. (2008) Netherlands	<p><b>Objectives</b> To stimulate “collaboration in dementia primary care” and “increase the number of cognitive assessments and dementia diagnoses and to improve attitudes and knowledge of GPs (general practitioners) and nurses.”</p> <p><b>Study design</b> Study Protocol for an outcome assessor-blinded randomised controlled trial. Future evaluation will be based on will be based on this study protocol. The study protocol calls for 100 pairs of general practitioners (GPs) and nurses to be recruited to the study, with 65 pairs randomized to the intervention group and 35 pairs randomized to the control group.</p> <p><b>Participants</b></p> <p><i>Baseline (data not yet collected)</i></p> <ul style="list-style-type: none"> <li>- 65 intervention GP-nurse pairs (data not yet collected)</li> <li>- 35 control GP-nurse pairs</li> </ul> <p><i>9-month follow-up (data not yet collected)</i></p> <ul style="list-style-type: none"> <li>- 65 intervention GP-nurse pairs (data not yet collected)</li> <li>- 35 control GP-nurse pairs</li> </ul>	<p>The EASY care-based Dementia Training Program was intended to offer training to pairs of GPs and nurses to improve professional performance, attitudes, and knowledge with respect to dementia. The training program was developed on the basis of Dementia Guideline for Primary Care (Perry et al. 2006, published in Dutch). GPs and nurses recruited to the study will be randomized to the intervention or to the control group to receive no training (however, the control group can participate in the training program after the study closes). GP-nurse pairs in the intervention group will attend one workshop on the topic of collaboration together, followed by a second workshop on the topic of dementia care separately. During the following 9 months, GPs and nurses will provide dementia care to patients within their own practice. GPs will be coached by a GP specialist in dementia, and nurses will be coached by a geriatric nurse; GPs and nurses will keep a diary during this coaching phase. After the coaching phase, GPs and nurses will have access to coaches by email and phone. GPs and nurses will receive diagnostic work-up support from a computerized clinical decision support system.</p>	<p>The EASY care-based Dementia Training Program was intended to recruit and teach pairs of GPs and nurses to collaborate in diagnosing dementia early and dementia management. For the FP-nurse pairs, the training program was intended to provide individual coaching (case-based consultation), 2 small group interactive workshops, and a computerized clinical decision support system.</p>	<p><i>Patient outcomes</i></p> <ul style="list-style-type: none"> <li>Number of emergency calls</li> <li>Visits to healthcare providers</li> <li>Satisfaction</li> </ul> <p><i>Caregiver outcomes</i></p> <ul style="list-style-type: none"> <li>Caregiver Burden Satisfaction</li> </ul> <p><i>Healthcare provider outcomes</i></p> <ul style="list-style-type: none"> <li>Number of cognitive assessments</li> <li>Number of dementia diagnoses</li> <li>Adherence to dementia guidelines</li> <li>Attitude</li> <li>Confidence</li> <li>Knowledge</li> </ul>	<p>The study has not yet been conducted and results have not yet been reported.</p>

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
17. Vickrey et al. (2006) US	<p><b>Objectives</b> To “test the effectiveness of a dementia guideline-based disease management program on quality of care and outcomes for patients with dementia.”</p> <p><b>Study design</b> Cluster randomized controlled trial: Patients from 18 primary care urban clinics were recruited to the study, with patients from 9 of these clinics receiving intervention care and patients from 9 of the clinics receiving usual care. 1,043 patients were identified via administrative databases as 65 years or older, with a dementia diagnosis code or cholinesterase inhibitor prescription during the previous 12-month period. Eligible patients with a caregiver were contacted by mail with consent forms and a caregiver baseline survey. 408 patient-caregiver pairs participated in the study at baseline, 361 pairs at 12-month follow-up, and 290 pairs at 18-month follow-up.</p> <p><b>Participants</b> <b>Baseline</b> - 238 intervention patients (54% women, average age 80 years) - 238 intervention caregivers (69% women, average age 66 years) - 170 control patients (56% women, average age 80 years) - 170 control caregivers (69% women, average age 65 years) - 166 healthcare providers (43% women, 89% physicians and 11% nurse practitioners)</p> <p><b>Follow-up (demographic data not reported)</b></p>	<p>ACCESS Study (Alzheimer’s Disease Coordinated Care for San Diego Seniors) to improve quality of dementia care was based on the Chronic Care Model (Wagner et al., 1996); a steering committee chose 23 dementia recommendations and developed a standard assessment, and protocols for referrals and coordinating care. Patients and caregivers in the control group receive usual care. Patients and caregivers in the intervention group were contacted by a dementia care manager (social worker) and assessed in their home. Within one month, care managers and caregivers reviewed the assessment together and collaborated to develop a care plan. Care managers provided caregivers with problem-solving skills and set care plans into motion. Care managers provided patient’s primary care physicians and other healthcare providers with a patient assessment summary and recommendations. Healthcare providers were able to attend education seminars on dementia care issues.</p>	<p>The ACCESS Study (Alzheimer’s Disease Coordinated Care for San Diego Seniors) program included dementia care managers (social workers) and communication with staff from community organizations and agencies. Care managers maintained a care management manual with management protocols and a computerized system to track patient follow-up. Care managers were responsible for patient follow-up based on need and performing 6-month reassessments in patients’/caregivers’ home.</p>	<p><b>Patient outcomes</b> Patient’s overall health care quality (rated by caregiver) Patient use of cholinesterase inhibitors (rated by caregiver)</p> <p><b>Caregiver outcomes</b> Community services received Knowledge about dementia Health state Confidence Mastery of caregiving Caregiver health-related quality of life (EuroQol-5D) Social support Unmet need for behavioural management assistance</p> <p><b>Healthcare provider outcomes</b> Adherence to 23 dementia guidelines</p>	<p><b>Patient outcomes</b> Patients in the intervention group were significantly more likely than patients in the control group to be taking a cholinesterase inhibitor at either 12-month or 18-month follow-up. Decline in patient quality of life between baseline and 18-month follow-up was significantly smaller in intervention patients than in control patients. Patients’ healthcare quality was significantly higher at 12-month and 18-month follow-up for intervention than control patients.</p> <p><b>Caregiver outcomes</b> Caregivers in the intervention group had significantly greater confidence and mastery at 18-month follow-up than caregivers in the control group. Caregivers in the intervention group had significantly greater social support than control group caregivers, at 18-month follow-up. Intervention group caregivers were significantly less likely than control group caregivers to report unmet need for behavioural management assistance.</p> <p><b>Healthcare provider outcomes</b> Healthcare providers in the intervention group were significantly more likely than providers in the control group to adhere to dementia guidelines.</p>

Authors (Year) Country	Study objectives, design, and participants	Intervention and duration	Healthcare provider(s)	Outcome measures	Results
18. Wood et al. (2003) UK	<p><b>Objectives</b> To “evaluate outcomes for carers receiving the Admiral Nurse Service, a specialist mental health nursing service for carers of people with dementia.”</p> <p><b>Study design</b> Comparison group quasi-experimental design compared 4 Admiral Nurse (AN) teams in an urban setting with 4 multi-disciplinary community mental health teams (CMHTs) for older people. Caregivers of patients with probable dementia diagnosis referred to AN services were recruited to the study. 128 caregivers were recruited and completed a baseline interview, and 104 completed an 8-month follow-up.</p>	<p>Caregivers of persons with probable dementia newly referred to one of four Admiral Nursing (AN) services were assigned to either the intervention group (AN) or to the control group of other specialist mental health services for older people. These control groups included multi-disciplinary teams comprised of community psychiatric nurses, occupational therapists, clinical psychologists, psychiatrists, and social workers; one team comprised of psychiatrists and a community psychiatric nurse, and a Memory Clinic service.</p>	<p>Admiral Nurses (ANs) are specially trained in dementia care. ANs work mainly with caregivers rather than patients, and specialize in providing dementia care. ANs providing services to a caregiver may or may not work with the person with dementia. ANs provide one-on-one support and coordinate informational, emotional, and practical support “throughout the caregiving career”, as long as a caregiver requires their services.</p>	<p><i>Patient outcomes</i> Institutional placement Clinical Dementia Rating (CDR) Quality of relationship with caregiver (Bergman)</p> <p><i>Caregiver outcomes</i> Health: somatic symptoms, anxiety and insomnia, social dysfunction, severe depression (General Health Questionnaire)</p>	<p><i>Patient outcomes</i> At 8-month follow-up, there were no significant differences in the proportion of patients who remained at home and patients who had moved to a nursing home or were in hospital.</p> <p><i>Caregiver outcomes</i> Anxiety and insomnia among caregivers in the intervention group were more likely than among control group patients to decrease at 8-month follow-up. No other caregiver health outcomes were significantly different between the intervention and treatment groups.</p>

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