

Article

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Identifying Primary Care Models of Dementia Care that Improve Quality of Life for People Living with Dementia and their Care Partners: An Environmental Scan

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Résumé

La démence est un enjeu de plus en plus préoccupant au Canada, qui affecte la santé de la population et augmente le coût des soins. Une analyse environnementale a été effectuée entre juin et octobre 2019 pour identifier les modèles, les stratégies et les ressources en soins de première ligne pour la démence dans onze pays présélectionnés, et leurs impacts sur les mesures de qualité de vie. Les stratégies de recherche incluaient un examen rapide de la portée, une recherche de littérature grise et des discussions avec les parties prenantes. Dix-huit modèles de soins de première ligne pour les personnes atteintes de démence ont été répertoriés. Les facteurs communs comprenaient les soins en équipe, la centralisation des soins et la coordination des cas, les plans de traitement individuels, une approche de soins par étapes et le soutien aux aidants. Cinq provinces avaient publié une stratégie en matière de démence. Des résultats positifs ont appuyé les modèles de soins de première ligne pour la démence, mais un seul modèle a démontré un impact sur la qualité de vie. Bien que ces résultats soient encourageants, de plus amples recherches sont nécessaires pour identifier les modèles de soins de première ligne qui améliorent sensiblement la qualité de vie des personnes atteintes de démence et de leurs aidants.

Abstract

Dementia is a growing concern in Canada, affecting peoples' health and raising the cost of care. Between June and October 2019, we conducted an environmental scan to identify primary care models, strategies, and resources for dementia care from 11 pre-selected countries and assess their impact on quality-of-life measures. Search strategies included a rapid scoping review, grey literature search, and discussions with stakeholders. Eighteen primary care-based models of dementia care were identified. Common factors include team-based care, centralized care/case coordination, individual treatment plans, a stepped-care approach, and support for care partners. Five provinces had released a dementia strategy. Evidence of positive outcomes supported primary care-based models for dementia care, although only one model demonstrated evidence of impact on quality of life. Although these findings are encouraging, further research is needed to identify primary care-based models of dementia care that demonstrably improve quality of life for people living with dementia and their care partners.

Introduction

Dementia is a serious issue in Canada, affecting nearly half a million Canadians (Bergman, 2019; Government of Canada, 2019) and costing the health system \$15 billion a year to manage (Bray, Strachan, Tomlinson, Bienek, & Pelletier, 2014). In an effort to address this problem, the Canadian Government launched a National Dementia Strategy in 2019, which provides a central vision for the effective treatment of dementia (Government of Canada, 2019). Among the strategy's key objectives is to “prioritize quality of life for people living with dementia and caregivers” (Government of Canada, 2019). One way to support this goal is by

refocusing dementia care to take place more in community and primary care settings, which are better situated for early detection of cognitive issues and coordination of care (Bergman, 2019; Warrick, Prorok, & Seitz, 2018). However, the complex nature of dementia and the needs of those living with dementia and care partners make it particularly challenging for primary care providers to deliver dementia care without additional resources (Pimlott et al., 2009).

The Canadian Foundation for Healthcare Improvement (CFHI) is a not-for-profit organization funded by Health Canada to create partnerships and spread innovations supporting better health care delivery. They have sought to identify innovations to support the implementation of key pillars in the National Dementia Strategy and inform a potential program focused on strengthening community- and primary care-based dementia care, in partnership with organizations, health care providers, and people with lived experience across Canada, with a particular focus on early diagnosis of dementia, care coordination, and navigation of care for people living with dementia (PLWD) and their care partners.

In support of the CFHI's community-based dementia care program development, we conducted an environmental scan to (1) identify primary care-based models of dementia care appearing in published literature, (2) identify dementia-related strategies and resources supporting the implementation of these models, and (3) examine models' effectiveness in improving quality of life for PLWD and their care partners.

The results of this study are relevant not only for the CFHI's program development, but also for those seeking to gain a comprehensive understanding of dementia care delivery and support in primary care settings across Canada.

Methods

Design

We used a multi-method approach to identify and examine models, strategies, and resources for dementia care, with a focus on those that currently exist in Canada. Our methods included (1) a scoping review of academic literature identifying primary care-based models of dementia care and their impact on quality of life, (2) a grey literature scan to identify existing provincial and territorial strategies and programs, and (3) discussions with stakeholders in our working group to identify additional resources and literature about dementia care delivery. To ensure that the results of the study would be relevant to stakeholders, particularly PLWD and their care partners, we used a co-design approach, defined as "the co-construction of research through partnerships between researchers and people affected by and/or responsible for action on the issues under study" (Jagosh et al., 2012).

Working Group

In June of 2019, we formed a small working group consisting of one person living with early-onset dementia, four care partners to PLWD, three CFHI staff, and four researchers. The stakeholders were all based in Ontario, except for one, who was in Alberta. Several members are actively involved in national-level organizations and initiatives related to dementia care. The working group held weekly meetings between July 19, 2019 and September 27, 2019 to oversee the study design, data collection, and analysis.

Data Collection

Scoping review

Rationale

We chose to conduct a scoping review instead of a systematic review because of the paucity of literature related to primary care models of dementia care and evidence for their effectiveness in improving quality of life. Unlike a systematic review, a scoping review is guided by a requirement to identify all relevant literature regardless of study design, and often leads to the identification of gaps in knowledge that are suitable for more in-depth pursuits via other methodologies (Gerstain Science Information Centre, 2019; Munn et al., 2018).

Methodological framework

For our scoping review, we followed the methodological framework outlined by Arksey and O'Malley, which outlines five steps to conducting a successful scoping study: (1) identify the research question; (2) identify relevant studies; (3) modify study selection based on post-hoc familiarity with the topic; (4) chart the data; and (5) collate, summarize, and report the results (Arksey & O'Malley, 2005). Step One was completed in consultation with our working group as described, and Step Five is described in the Results. The remaining steps are denoted in the Methods.

Search strategy

In consultation with a librarian at the University of Ottawa, we developed a search strategy (Step Two) to capture the key concepts pertinent to the review (dementia, model, primary care, patients, and quality of life) using subject heading terms and keywords (Appendix A). The search terms for these five concepts were combined to search the MEDLINE[®], Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and Cochrane Library databases. Searches in MEDLINE, Embase, and PsycINFO were run simultaneously in Ovid, whereas the search in CINAHL was run separately through EBSCOhost. We limited our search to publications that were in French or English and published between January 2009 and July 2019. No limitations were put on publication type. Search results were combined in Covidence, a review management software (<https://www.covidence.org/>), and de-duplicated.

Inclusion/exclusion criteria

Article inclusion and exclusion criteria were established in consultation with the librarian and working group. Articles were included if they explored a primary care-based intervention, described a model of care, applied to early and middle stages of dementia, presented outcomes related to quality of life, and originated from any of the 11 countries reported on by the Commonwealth Fund's International Health Policy Survey of Older Adults (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States) (Canadian Institute for Health Information, 2017).

Reviewers (trained researchers and CFHI staff members) determined article inclusion by examining the title, abstract, and full text. Two reviewers completed title and abstract screening in both official Canadian languages: I.M. and M.H. for English articles and T.M. and M.M. (a non-author staff member at CFHI) for French articles. Reviewers met to discuss any disagreements (Step Three). Articles deemed relevant in the title and abstract screen moved forward to the full-text review (completed by researchers I.M. and A.M.), as did any articles for which the relevance was unclear based on the information in the abstract. Citations of included articles

were screened for further references to include. We did not limit publications by country at this stage.

Data extraction

Data extraction took place between July and October 2019 (Figure 1). Three reviewers (researchers I.M., C.S., and M.H.) extracted data from eligible studies using a data extraction spreadsheet created in Microsoft Excel 2016 (Step Four). The following data elements were extracted from each article: country, study type, setting, type of intervention (e.g., screening tool, model of care), brief description, patient population (including sample size, dementia stage, and diagnostic techniques), intervention target group (e.g., patients, providers, and care partners), intervention delivery agent, key outcomes, and notes/observations.

Grey literature search

We conducted a grey literature search between July 19 and 22, 2019 to identify existing dementia strategies and programs in Canadian provinces and territories. The initial search was based on Appendix B of the National Dementia Strategy, as it provided a general overview of provincial and territorial dementia-related initiatives at the time (Government of Canada, 2019). We identified provinces and territories that had released dementia strategies or frameworks. We also conducted a Google search to identify additional specific programs existing in the provinces and territories, using the following search structure: “[province/territory name] dementia program”.

Stakeholder identification of resources and literature

Concurrent with the scoping review and grey literature scan, working group members identified additional resources relevant to dementia care delivery and academic literature describing models of care. These were shared among group members via e-mail and discussed at working group meetings. All were considered within the context of the scan and included if relevant.

Data Analysis

Data analysis was conducted with members of the stakeholder working group using a thematic analysis with constant comparison approach. Results were iteratively presented to the group and discussions were facilitated to identify key outcomes of interest, interpret the findings, and identify gaps. The perspectives of PLWD and their care partners were explicitly sought during and between meetings.

Scoping review

Characteristics of identified articles, descriptions of the models of care, and the reported outcomes were summarized and tabulated. Reported findings were categorized and are summarized in the main text. Through qualitative synthesis and categorization, we identified key and common components of each model. Descriptions are provided.

Grey literature search

Provincial and territorial strategies and programs identified in the grey literature were collated into an inventory and visualized geographically. Evaluation of the impact, effectiveness, or reach of these was outside the scope of this scan.

Stakeholder identified resources and literature

Resources and literature identified by stakeholders and not captured in the academic scoping review or grey literature search were collated into an inventory. No evaluation of the impact, effectiveness, or reach of these resources or models of care was completed as part of this environmental scan.

Results

Objective 1: Identify Published Primary Care Models of Dementia Care

The scoping review retrieved a total of 901 articles, of which 27 met inclusion criteria (Figure 2). Among the 27 studies, 17 described 13 different primary care-based models of dementia care for people in the early and middle stages of dementia (Ament et al., 2015; Blumenthal et al., 2014; Clevenger, Cellar, Kovaleva, Medders, & Hepburn, 2018; Fortinsky et al., 2014; Iliffe et al., 2014; Jansen et al., 2011; Jennings, Ramirez, Hays, Wenger, & Reuben, 2018; Kohler et al., 2014; LaMantia et al., 2015; Meeuwse et al., 2012; Michalowsky et al., 2019; Phung et al., 2013; Reilly et al., 2015; Sogaard et al., 2014; Sørensen, Waldorff, & Waldemar, 2008; Thyrian et al., 2017; Waldorff et al., 2012), four described educational interventions for providers (Menn et al., 2012; Perry et al., 2011; Pond et al., 2018; van den Dungen et al., 2016), three presented screening tools (Arevalo-Rodriguez et al., 2015; Barnes et al., 2014; Janssen et al., 2017), one discussed dignity therapy (Johnston et al., 2016), one reviewed various screening tools and models (Geldmacher & Kerwin, 2013), and one presented a general discussion on the benefits of early diagnosis of Alzheimer's disease (Allan et al., 2013). Details of included studies are available in Table 1, while descriptions of the models of care identified in the studies can be found in Table 2.

Of the 17 articles that described primary care-based models of dementia care for people with early- and middle-stage dementia, 8 were randomized controlled trials, 2 were reviews, and 7 used other research designs. Most articles featured multi-component, collaborative models of care. These models often utilized other service providers (e.g., specialized nurses or other allied health professionals) to coordinate and deliver medical and non-medical care to PLWD and care partners. Several common core components characterized the models: (1) a team-based approach involving collaboration among primary care physicians, specialists, care/case managers, and care partners; (2) a care/case manager responsible for care coordination and integration across a broader provider network and community resources; (3) development of an individualized care/treatment plan that is regularly monitored and adaptable to changing needs; (4) a stepped-care approach, with targeted specialty consultation available for more complex cases as needed, and (5) consideration of the care partner's needs along with those of the PLWD.

In addition to the models of care identified through the scoping review, the PLWD, their care partners, and CFHI staff members in the working group identified five distinct models of dementia care published in the literature, two based in Canada (Health Innovations Group, 2019; Lee et al., 2010, 2018; Lee, Hillier, Locklin, Lumley-Leger, & Molnar, 2019; Rural Dementia Action Research, 2019) and three that were international (Buurtzorg, 2019; Nadash, Silverstein, & Porell, 2019; Renehan, Goeman, & Koch, 2017) (Table 3). All models featured elements of collaborative care, and included memory clinics and variations of care/case management. None of the models included any evaluation of impact on quality of life. However, the Multispecialty INterprofessional Team-based

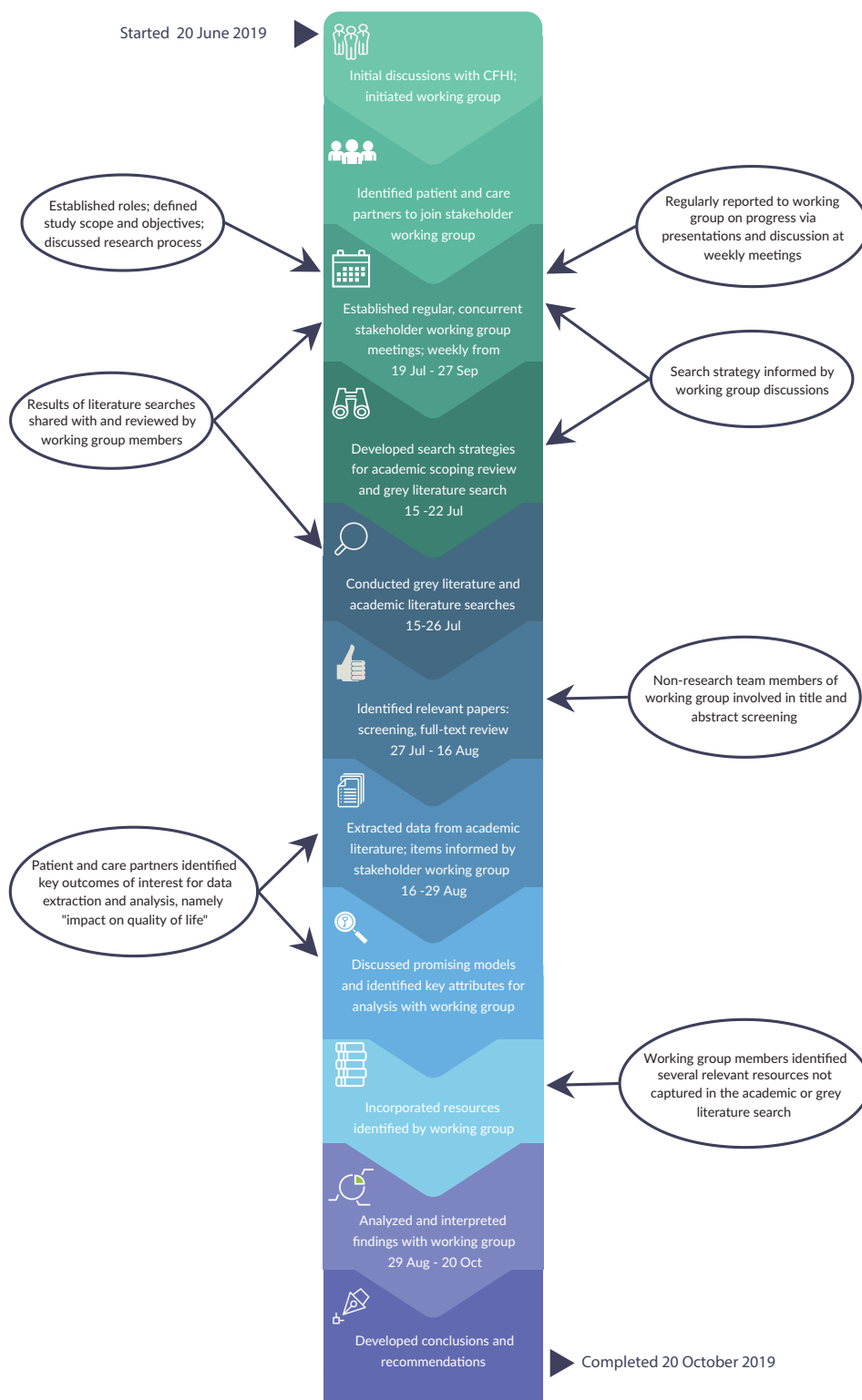


Figure 1: Timeline of the environmental scan to identify models, strategies, and resources for dementia care in Canada

(MINT) Memory Clinics led in Ontario, which address the issue of access to dementia care in primary care by coordinating and streamlining an interdisciplinary assessment, have recently undergone evaluation and shown positive outcomes. These include high

levels of patient and care partner satisfaction with the clinics and strong satisfaction with the training and support provided by physicians and allied health professionals (Health Innovations Group, 2019). Challenges identified included sustainability at both

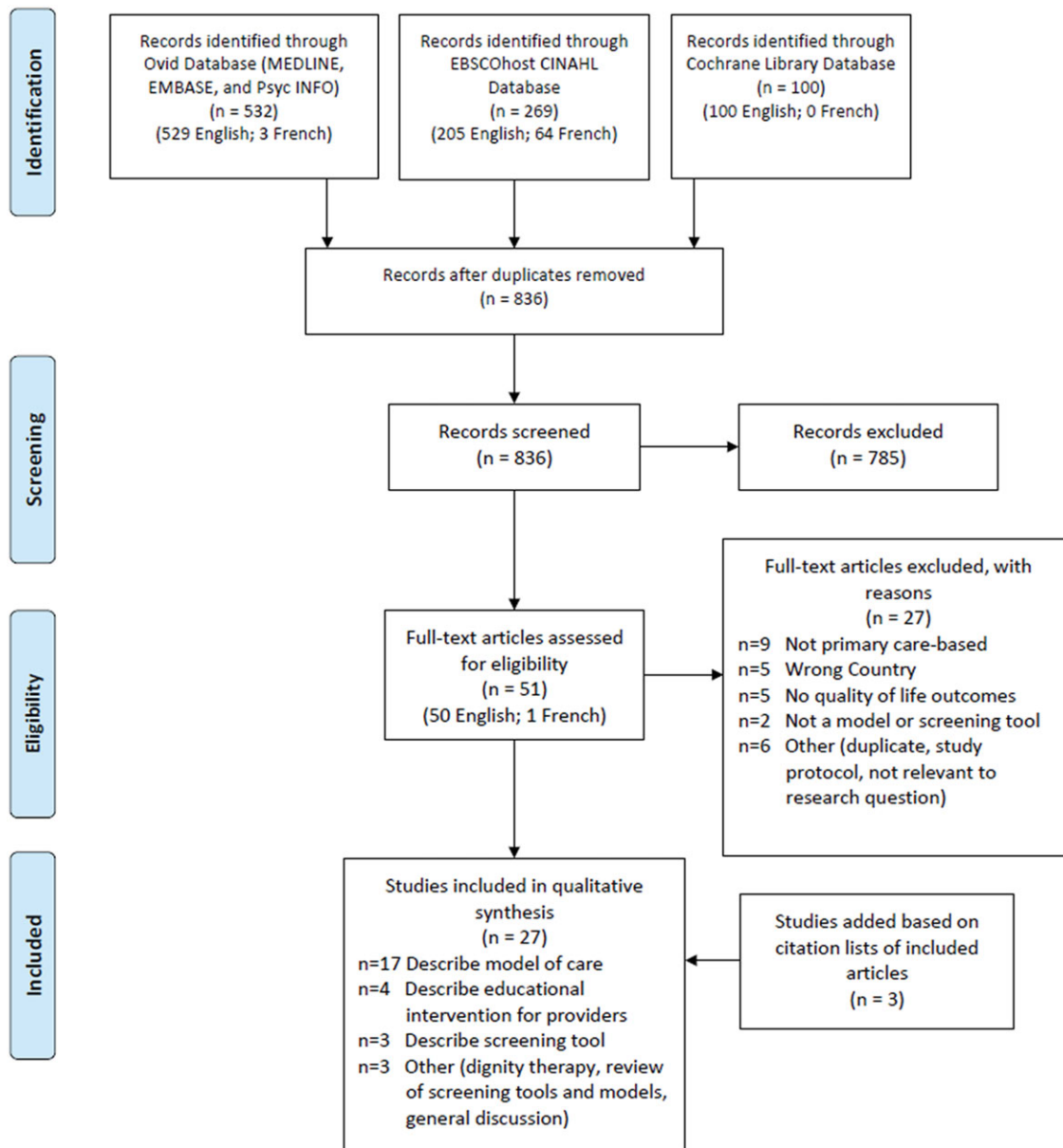


Figure 2. Flow diagram demonstrating inclusion and exclusion of articles during scoping review

a stewardship and an operational level, in addition to different resource models and levels of integration between primary care and specialist physician care across the province (Health Innovations Group, 2019).

The working group also identified three other pieces of literature relevant to this summary of dementia care models: a strategic framework for a regional model of dementia care (Champlain Dementia Network, 2013), a systematic review of case manager collaboration models (Khanassov & Vedel, 2016), and a review of caregiver- and patient-directed interventions (Health Quality Ontario, 2008).

Objective 2: Identify Strategies and Resources Supporting Dementia Care

Through our grey literature search, we identified only five provinces that had released a dementia strategy: British Columbia,

Alberta, Manitoba, Quebec, and Nova Scotia (Alberta Government, 2017; Bergman, 2009; British Columbia Ministry of Health, 2016; Manitoba, 2014; Province of Nova Scotia, 2015) (Figure 3). However, programs supporting PLWD existed in every province and territory except the Yukon and Nunavut. The Alzheimer Society operated in all these jurisdictions (Alzheimer Society of Canada, 2019a), where it often provided such programs as First Link® (a referral program for people recently diagnosed with dementia) (Alzheimer Society of Canada, 2019b) and Minds in Motion® (an exercise regimen supporting physical and mental stimulation) (Alzheimer Society of B.C., 2019), as well as a helpline and general dementia education services. Programs unique to certain provinces included Music&Memory® in Quebec (Société Alzheimer de l'Estrie, 2019), Memory Café in New Brunswick (Alzheimer Society of New Brunswick, 2019), Brain Fitness Fun in Prince Edward Island (Alzheimer Society of PEI, 2019), and the Village Langley in British Columbia (Village Langley, 2019).

Table 1: Characteristics of studies included in scoping review

Citation	Country	Study Type	Setting	Patient Population	Intervention
Allan, Behrman, and Ebmeier (2013) Early diagnosis beneficial in Alzheimer's disease	UK	General discussion/ opinion	n/a	n/a	Early diagnosis; various tools discussed
Ament et al. (2015) The benefit of a geriatric nurse practitioner (GNP) in a multidisciplinary diagnostic service for people with cognitive disorders	The Netherlands	Observational study with two cohorts: an intervention group and a historical reference sample	Community mental health facility and general practices	114 patients with added GNP compared with a historical reference sample (n=137). All patients were diagnosed with dementia	Adding a GNP to an outpatient diagnostic multidisciplinary facility for psychogeriatric patients
Arevalo-Rodriguez et al. (2015) Mini-Mental State Examination (MMSE) for detection of Alzheimer's disease and other dementias in people with mild cognitive impairment	Sweden (2), Spain (4), France, USA (2), and Japan (2)	Cochrane review	Community, primary care, and secondary care	Patients clinically classified as individuals with mild cognitive impairment (MCI) at baseline	MMSE tool
Barnes et al. (2014) Development and validation of a brief dementia screening indicator for primary care	USA	Validation study using data from four large, ongoing cohort studies	Primary care	Age ≥65, dementia free, community dwelling at baseline from four cohorts: Cardiovascular Health Study (CHS), Framingham Heart Study (FHS), Health and Retirement Study (HRS), and Sacramento Area Latino Study on Aging (SALSA)	Dementia Screening Indicator
Blumenthal et al. (2014) Dementia Evaluation, Management, and Outreach (DEMO)	USA	Program evaluation	Regional community-based outpatient clinics that serve veterans	132 veterans with mild-to-moderate cognitive impairment with mean and significant functional limitations	DEMO program
Clevenger, Cellar, Kovaleva, Medders, and Hepburn (2018) Integrated Memory Care Clinic (IMCC): Design, Implementation, and Initial Results	USA	Program evaluation	Patient-centred medical home	139 patient-caregiver dyads. Patients had a confirmed diagnosis of dementia or mild cognitive impairment. 53.2% had Alzheimer's disease	IMCC
Fortinsky et al. (2014) Results and lessons learned from a nurse practitioner-guided dementia care intervention for primary care patients and their family caregivers	USA	Quasi-experimental practice-based research study (a non-equivalent control group design)	Primary care practices	31 patient-caregiver dyads; 21 dyads in the intervention group and 10 dyads in the control group. Patients had to have a diagnosis of irreversible dementia, arteriosclerotic dementia, senile dementia, pre-senile dementia, mild memory loss, or Alzheimer's disease	Proactive primary dementia care (PPDC) nurse practitioner-guided dementia care

Table 2: Models of dementia care identified through the scoping review

Name	Brief Description	Impact
Dementia Care Management (DCM)	A model of collaborative care, aiming to support persons with dementia and their caregivers through coordination and management of optimal treatment and care. It is delivered by nurses with dementia-specific qualifications supported by a computer-assisted intervention management system to improve systematic identification of patients' and caregivers' unmet needs (care, medical, and social). The interdisciplinary team creates an individual treatment plan, and the nurse carries out intervention tasks in cooperation with the caregiver, general practitioner (GP), and health care providers.	DCM increased patient quality of life and decreased caregiver burden and dementia symptoms. There was no significant effect on patient's cognitive status or function. It was shown to be cost effective (from the payer's perspective).
Aging Brain Care (ABC) Medical Home	A population health management program that builds on collaborative dementia (and depression) care program led by a registered nurse, who serves as a care coordinator (CC) and supervises a group of 5 care coordinator assistants (CCAs). The CCA conducts initial assessment and meets with the CC and the social worker to develop an individualized care plan that includes a set of pharmacological and psychosocial protocols targeting the individual and the informal caregivers. The team continuously adjusts the individualized care plan. The team uses a "mobile office" in its day-to-day work that allows it to meet individuals at home, their primary care physician's office, or any other safe location of their choosing.	The ABC Medical Home reduced individuals' and informal caregivers' reported cognitive, functional, behavioral, and psychological dementia symptoms.
Integrated Memory Care Clinic (IMCC)	The IMCC is situated within a patient-centered medical home as defined by the National Committee for Quality Assurance. Advanced practice registered nurses (APRNs) are the first-line clinicians. They collaborate with a neurologist and a geriatrician, but patients do not have physician appointments except when the APRNs order specialist consultations. IMCC's co-production model of care prioritizes patient and caregiver goals.	IMCC reduced hospitalizations and showed high caregiver satisfaction.
Dementia treatment and care coordination by memory clinics	Memory clinics provide treatment and care coordination based on the specialist Dutch dementia guidelines. The main content includes prescribing and guidance of anti-dementia drugs (cholinesterase inhibitors and memantine) and non-drug interventions (e.g. occupational therapy, providing day structure, or referral to a nurse specialist, day care, or home care), both delivered on a tailored basis.	A comparison between post-diagnosis care provided by a memory clinic vs. a GP showed no significant difference in patient or caregiver outcomes, treatment, or care coordination.
Early psychosocial counselling and support program – Danish Alzheimer Intervention Study (DAISY)	Multicomponent semi-tailored intervention program directed at newly diagnosed individuals and their caregivers, intensive in both content and duration, which targeted multiple needs of caregivers and patients in a tailored fashion. It offered participants several components: counselling sessions, courses, and additional support via phone calls.	No improvements in outcomes for patients and their caregivers were found at the 12-month or 3-year follow ups, compared with usual care. Was found unlikely to be cost effective from a societal perspective (which included the costs of health care, social care, informal care and production loss). A qualitative study linked to this trial showed that 80% of patients and 94% of caregivers in the intervention group found the intervention beneficial, describing it as stimulating and rewarding. It supported patient self-esteem and improved patients' and caregivers' ability to cope with the challenges of everyday life and social relations. There were no apparent negative outcomes of the intervention.
Proactive Primary Dementia Care (PPDC) Nurse Practitioner-Guided Dementia Care	A nurse practitioner trained in geropsychiatry conducted in-home visits to people living with dementia and their caregivers to coordinate and deliver medication management and non-pharmacological treatments, in collaboration with a group of clinicians at primary care clinics.	There was no impact on patient and caregiver outcomes over the 12 months, but providers reported improved patient mood and outlook. There was an extremely high level of satisfaction expressed by patients, caregivers, and providers participating in the PPDC intervention.

(Continued)

Table 2: Continued

Name	Brief Description	Impact
Geriatric nurse practitioner (GNP) in an outpatient diagnostic multidisciplinary facility	One GNP was appointed within the Diagnostic Observation Center for PsychoGeriatrics (DOC-PG) facility, which provides multidisciplinary assessment and therapeutic advice for patients with cognitive disorders, to communicate the diagnosis and advice to all the GPs who referred patients to the facility. The GNP functioned as a mediator between the DOC-PG facility and the GP and, in addition, was a contact person for informal caregivers and patients.	Intervention increased physician concordance with advice formulated by the DOC-PG team, lowered caregiver burden, and had no impact on patient or caregiver quality of life.
Dementia Evaluation, Management and Outreach (DEMO) Program	A full-time geriatric nurse practitioner and a psychology technician were added to the multidisciplinary team to (1) extend dementia evaluations to regional community-based outpatient clinics that serve veterans in outlying regions; and (2) improve the management and the follow-up that these veterans receive. They conducted dementia evaluations (neuropsychological testing, medical records review, caregiver interviews, and patient examinations). The data were then brought back to the full geriatrics/dementia clinic multidisciplinary team for discussion. The team reached a consensus diagnosis and then made a comprehensive plan for the further evaluation and management of these complex patients. The plan was entered into the computerized patient record system and communicated to the patient and caregiver. Services included regular phone calls and case management services that augmented those of their primary care provider.	By bringing specialized services to geographically isolated patients, the DEMO program was able to increase both access and utilization. The DEMO program was enthusiastically received by patients, and caregivers reported overall satisfaction with the services received—100% and 98%, respectively—and 93% of caregivers indicated satisfaction with how the program met their needs. DEMO did not seem to have any effect on overall inpatient bed days, primary/home-based care visits, or total costs.
Interdisciplinary Care and Treatment network for people with Dementia in the Uckermark (IdemUck) regional dementia network	IdemUck is an interdisciplinary regional network for dementia care and treatment. Network members include GPs, medical specialists, social workers, hospitals, and other outpatient and inpatient setting workers, with the GPs acting as the gatekeepers and information holders. GPs ascertain medical history, conduct standardized neuropsychological screening tests, and, if necessary, recommend consultations with various specialists inside the network. Throughout the course of disease, the GP offers first access and successive admission to health and social services and treatment, collects all diagnostic findings, and monitors the course of treatment.	This model improved treatment and care aligning with dementia guidelines, but it did not have an impact on quality of life or other caregiver and patient outcomes.
Case management by district nurses (in-home setting)	District nurses (similar to nurse practitioners) acted as case managers and delivered care to people living with dementia and their caregivers in their home setting. They evaluated patient and caregiver needs, developed care plans with patients and caregivers, delivered care, initiated referrals, and monitored outcomes. They communicated with the primary care providers and met monthly with other case managers.	This model showed no benefit to quality of life or care outcomes, although there was high caregiver satisfaction.
CAREDEM case management (in general practice setting)	The CAREDEM collaborative case management approach was designed to be embedded into primary care, to enable better management of common problems in dementia. The case manager was often, but not always, a nurse. The role was designed to be performed by practitioners located within primary care and working in liaison with secondary care services, to provide a multiprofessional care coordination approach: supporting patients at the time of diagnosis, managing breakdown of support systems, managing acute illness and hospital admission, supporting decisions about relocation, and supporting the person with dementia and his or her family at the end of life.	The model did not show significant gains for patient outcomes and was difficult to implement in the UK setting.

(Continued)

Table 2: Continued

Name	Brief Description	Impact
Case management (systematic review)	Case management models from studies included in this systematic review varied in components and delivery. The core tasks included assessment, care planning and implementation/ management of care, including care plan monitoring. Other tasks associated with more complex care coordination included arranging and allocating services and managing the care network (coordinating family care, empowering the carers and people with dementia to make use of their social support network, establishing support from community groups or health care resources, and providing emotional support to carers). Case managers were most often nurses or social workers and many collaborated with a multidisciplinary team or another medical professional.	This systematic review evaluating case management models showed no clear long-term benefits for patient outcomes. Considerable heterogeneity between the interventions, outcomes measured, and time points across the 13 included randomized controlled trials (RCTs) made it difficult to draw clear conclusions.
Goal setting and attainment in a dementia care management program (Alzheimer's and dementia care program)	The program uses nurse practitioners partnered with primary care providers and community-based organizations to address the comprehensive care needs of persons with dementia and their caregivers. Personalized health goals and action plans were specified and attainment was measured using goal attainment scaling (GAS). Dyads revised goals or set new goals at 6 months, if desired.	Most goals (84%) that persons with dementia and their caregivers identified were not related to medical care; instead, they focused on broader aspects of quality of life (47%) or caregiver support (29%). Goal setting using GAS was shown to be feasible to establish and attain person-centred goals.

Table 3: Models of dementia care identified by working group

Name	Country	Brief Description
Rural and Remote Memory Clinic (RRMC) by the Rural Dementia Action Research (RaDAR)	Canada (Saskatchewan)	Led by Dr. Debra Morgan of the RaDAR team, the RRMC aims to increase the availability and accessibility of dementia care in rural and remote areas. The clinic streamlines assessment and diagnosis in order to reduce repeated travel over long distances and to shorten the time to diagnosis by coordinating an interdisciplinary assessment on one day. Clinic staff includes a neurologist, neuropsychologist, clinic nurse, psychometrist, physiotherapist, and research clerk. Originally implemented and evaluated through a Canadian Institutes of Health Research New Emerging Team (NET) Grant-funded research program, today the RRMC receives funding from the Saskatchewan Ministry of Health to provide clinical services to Saskatchewan residents.
Primary care collaborative memory clinics, also known as multi-specialty INterprofessional team-based (MINT) memory clinics	Canada (Ontario)	Led by Dr. Linda Lee, the MINT memory clinics provide access to high-quality dementia care within the local family physician's office. The model involves training primary care teams with a standardized, accredited program, and fostering collaboration with geriatric medicine, geriatric psychiatry, and cognitive neurology enabled by virtual consult. There are currently 112 MINT memory clinics across Ontario, many in rural and remote communities, with more to come.
The Dementia Care Coordination Program	United States	The dementia care coordination program described in the article by Nadash et al. (2019) was distinctive in using the medical system, rather than direct outreach, to identify and refer families to supports provided by an Alzheimer's Association chapter via dedicated care consultants. One care consultant received referrals from individual physicians, whereas the other, employed by a health plan, received referrals from health plan case managers. The results showed that the health plan model of collaboration offered significant potential for the systematic and early detection of potential clients.
Buurtzorg Model of Care	The Netherlands	A nurse-led model of holistic care in The Netherlands, the program empowers nurses to deliver all the care that patients need and encompasses self-management, continuity, building trusting relationships, and creating networks in the neighborhood to bring independence and improved quality of life. Buurtzorg scaled very quickly across the Netherlands from 1 to 850 teams in just 10 years.

(Continued)

Table 3: Continued

Name	Country	Brief Description
Australian dementia key worker models	Australia	Key worker support models are one approach that has been used to assist people living with dementia and their caring unit to coordinate services and navigate service system. They include health care workers in support roles to assist people living with dementia and their caring unit to coordinate services and navigate service systems. The titles for such support roles vary worldwide and include: key workers, support workers, case managers, care coordinators, dementia advisers; and Admiral Nurses. A published article by Renehan et al. (2017) offers a description of the key worker model by offering an optimized key worker framework, co-designed and developed by an expert working and reference group, and based on a systematic review of the literature and a qualitative evaluation of 14 dementia key worker models operating in Australia. The optimized framework consists of four main components: overarching philosophies, organizational context, role definition, and key worker competencies. The framework was informed and endorsed by people living with dementia and their caring unit, key workers, managers, Australian industry experts, policy makers, and researchers. An evaluation of its effectiveness and relevance for practice within the dementia care space is required.



Figure 3. Map of provincial and territorial strategies and programs for people living with dementia in Canada

In addition to the strategies and programs uncovered by the grey literature search, the working group identified 11 additional resources supporting dementia care in Canada. Through iterative discussion with our working group, we divided these resources into three categories: research networks, programs, and recommendations.

Research networks

Participants identified five research networks focusing on issues relevant to dementia (Table 4). Four of the identified networks operated in Canada (two of which were multinational) (Canadian

Consortium on Neurodegeneration in Aging, 2019; International Indigenous Dementia Research Network, 2019; Island Health, 2019; Rural Dementia Action Research, 2019), whereas the fifth was situated in Australia (Cognitive Decline Partnership Centre, 2019).

Programs for PLWD and their care partners

Participants identified three programs based in Canada for PLWD and their care partners, in addition to those found through the grey literature search (Alberta Health Services, 2011; Living the Dementia Journey, 2019; YouQuest, 2019). These included Memory

Table 4: Research networks identified by the working group

Name	Country	Brief Description
Rural Dementia Action Research (RaDAR)	Canada, UK	An interdisciplinary group of knowledge users and researchers from three Canadian provinces (Saskatchewan, Alberta, Ontario) and the UK aiming to improve health care delivery to people with mild cognitive impairment and dementia and their caregivers in rural and remote communities.
International Indigenous Dementia Research Network (IIDRN), Indigenous Cognition & Aging Awareness Research Exchange (I-CAARE)	USA, Canada, Australia	Seeks to highlight the profiles of researchers, students, Indigenous community members, and policy makers from around the world who share a commitment to research concerning Alzheimer's disease, dementia, and healthy aging in Indigenous peoples.
Canadian Consortium on Neurodegeneration in Aging; Theme 3: Quality of Life	Canada	Identifies several national research teams leading various dementia care interventions, which focus on improving the management of dementia and the quality of life of those with lived experience.
The Neil and Susan Manning Cognitive Health Initiative, Island Health	Canada	An innovative 5-year clinical research program with a goal to integrate leading-edge research and care for patients living with cognitive health issues on Vancouver Island.
Cognitive Decline Partnership Centre	Australia	A collaborative multidisciplinary research centre that provides quality research evidence in dementia care to clinicians, service providers, and policy makers with the goal of improving practice and service delivery.

P.L.U.S. (Practice, Laughter, Useful Strategies), a community-based education program that supports people with mild dementia and their care partners; the YouQuest therapeutic recreation program; and Living the Dementia Journey, an evidence-informed training program for those who support PLWD.

Recommendations related to dementia care

Participants identified three organizations that provided specific recommendations pertaining to dementia care. The Canadian Nurses Association published a report containing five proposals in support of improved dementia care, which included developing a national dementia strategy, shifting PLWD to community care, and supporting dementia-based education for nurses and other health care professionals (Canadian Nurses Association, 2016). Health Quality Ontario issued a quality standard for treatment of PLWD in the community, including guidelines for primary care, specialist care, hospital outpatient services, home care, and community support services (Health Quality Ontario, 2019). It also provided guidance on support for care partners of PLWD, and proposed measures of success at a provincial and local level. The American Academy of Neurology issued a press release encouraging annual cognitive screenings for people 65 years of age and older (American Academy of Neurology, 2019).

Objective 3: Examine Effectiveness of Models in Improving Quality of Life

The studies included in the scoping review used a variety of outcome measures and indicators to evaluate the models of care. However, only one model reported a positive impact on quality of life for PLWD (Michalowsky et al., 2019; Thyrian et al., 2017). This study assessed the Dementia Care Management (DCM) model, a computer-supported, collaborative care model-based intervention, characterized by a high intensity of care management and level of integration across health care and social services. Although designed to target cost effectiveness, the study by Michalowsky et al. used the 12-item Short-Form Health Questionnaire (SF-12) to assess health-related quality of life and calculate patients' Quality Adjusted Life Years (QALYs). They found an increase in QALYs over the study period (2019). A randomized clinical trial of DCM

also found a significant increase in quality of life among PLWD who did not live alone, although this did not extend to the overall sample (Thyrian et al., 2017). In this study, the Quality of Life in Alzheimer Disease instrument (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 2002) was used.

Another model that was thought to be promising was evaluated in the Danish Alzheimer Intervention Study (DAISY). The DAISY intervention is a psychosocial counselling and support program directed at newly diagnosed individuals and care partners, and it was the subject of a randomized controlled trial (Waldorff et al., 2012). Although a qualitative study showed benefits for PLWD and their care partners (Sørensen et al., 2008), it resulted in no statistically significant improvements in outcomes for PLWD and their care partners, including quality of life measurements, after 12 months (Waldorff et al., 2012) or at the 3-year follow up (Phung et al., 2013), compared with usual care.

Other outcomes that were reported about the models of care were reduced care partner burden (Michalowsky et al., 2019; Thyrian et al., 2017), increased patient/care partner satisfaction (Blumenthal et al., 2014; Clevenger et al., 2018; Fortinsky et al., 2014; Jansen et al., 2011; Sørensen et al., 2008), increased provider satisfaction (Fortinsky et al., 2014), improved compliance/alignment with dementia care recommendations/guidelines (Ament et al., 2015; Kohler et al., 2014), reduction in hospitalizations (Clevenger et al., 2018), decreased dementia symptoms (LaMantia et al., 2015; Michalowsky et al., 2019; Thyrian et al., 2017), and cost effectiveness (Michalowsky et al., 2019).

Discussion

Our environmental scan identified a total of 18 models supporting dementia in primary care—13 through the scoping review and 5 through working group discussions—alongside strategies and resources supporting the implementation of these models. Services supporting PLWD exist in nearly all provinces and territories, but published and adopted provincial strategies for dementia care were only identified for five provinces (British Columbia, Alberta, Manitoba, Quebec, and Nova Scotia).

Our scan identified several positive outcomes associated with primary care models for dementia, including improvements in PLWD, care partner and provider satisfaction, reduced hospitalizations, and improved compliance aligning with dementia care recommendations/guidelines. However, out of all the models reviewed, only one demonstrated an ability to improve quality of life for PLWD: the DCM model (Michalowsky et al., 2019; Thyrian et al., 2017). DCM is a highly flexible model that used a computer-based intervention management system to connect PLWD with a multi-professional team to support their care. Care is often delivered at home by nurses specializing in dementia care (Thyrian et al., 2017). A randomized clinical trial of the model demonstrated a significant increase in quality of life among PLWD not living alone, in addition to a decrease in behavioral and psychological symptoms of dementia (Thyrian et al., 2017), while a subsequent study examining cost effectiveness demonstrated an increase in QALYs among individuals receiving DCM-based treatment (Michalowsky et al., 2019). It should be noted that there are differences in the applicability and validity of the tools used to measure quality of life in this patient population, the SF-12 and QOL-AD (Geschke, Fellgiebel, Laux, Schermuly, & Scheurich, 2013). Despite this, DCM demonstrated substantial promise and should receive greater examination.

Comparison of the primary care models identified was challenging, because of the heterogeneity of the interventions, outcome measures, and time points examined, as previously reported in the literature (Backhouse et al., 2017; Reilly et al., 2015). However, in our review, several key components emerged that were consistent across programs. These precepts offer a strong template for effective service delivery, and bear keeping in mind for those looking to create or implement models of dementia care in primary care settings. First, models adopted a team-based approach, with clear guidelines to inform how primary care providers can offer dementia care in collaboration with other providers, family members, and the PLWD themselves. In every case but one, this was accomplished by retaining a central role for persons' existing primary care providers in the diagnosis and management of dementia (Clevenger et al., 2018). Second, models enlisted case managers responsible for coordination of medical, allied health, and community services. Third, models supported the development of individual treatment plans that were continually monitored and updated as necessary to reflect the PLWD's changing needs. Fourth, models used a stepped-care approach, providing links to specialty care and community resources. Lastly, models emphasized the importance of incorporating the care partner's needs along with those of the PLWD. It is worth further noting that these needs extend beyond medical services. An important finding of Jennings et al. (2018) was that most needs and corresponding goals (84%) that PLWD and care partners identified were not related to medical care, but instead focused on broader aspects of quality of life or care partner support. Likewise, our synthesis of existing literature revealed that there is a lack of evaluation and evidence regarding the impact of primary care-based dementia models on quality of life of PLWD and care partners, and that there is a need to improve the delivery of dementia care and support in primary care settings by focusing on quality of life as an essential outcome.

Our grey literature search identified publicly available dementia-related strategies in fewer than half of Canadian provinces and territories. This finding highlights significant equity issues regarding access to services for people affected by dementia. Provinces and territories that have not adopted guidelines should consider doing so, to ensure that PLWD and care partners in these jurisdictions are not overlooked. The strategic themes identified by Edick, Holland,

Ashbourne, Elliott, and Stolee (2017) from international literature provide a starting framework for these jurisdictions. Encouragingly, all jurisdictions except for two territories had some manner of program to support dementia care. Further, our scan included discussions with members of our own working group who had lived experience with dementia, in order to identify additional resources that the search may have missed. Through these discussions, we identified five models of dementia care and 11 resources. Some of these models featured elements of collaborative care similar to those identified in the scoping review, such as care/case management (Nadash et al., 2019; Renehan et al., 2017). Several resources featured interesting community-based programs identified for PLWD and/or care partners (e.g., Memory P.L.U.S. [Alberta], YouQuest therapeutic recreation model [Alberta], and Living the Dementia Journey [Ontario]). However, our study's scope did not include evaluation of these programs, necessitating further exploration of their impact on outcomes for PLWD.

Our co-design approach influenced the study's design, results, analysis, and interpretation. There is evidence that co-design has a favorable impact on health research by improving quality, acceptability, rigor, and relevance; building capacity; creating sustainability; and generating new insights and activities (Jagosh et al., 2012). In our own experience, our co-design approach was instrumental in shaping the study to best match PLWD and care partner perspectives and priorities. For example, our partners with lived experience emphasized that "impact on quality of life" was the outcome of most importance to them. This input guided our search strategy, data extraction, and analysis. These team members also described the gaps in care and supports that PLWD and their care partners experience, which informed interpretation. Given our experience and the supporting literature (Bergman, 2019; Jagosh et al., 2012), we recommend maintaining a co-design approach throughout program/service development and implementation, to ensure that such programs and services meet the needs of all stakeholders, particularly PLWD and their care partners. Key impact outcomes, such as quality of life, should be defined at program onset.

This environmental scan was conducted with a rigorous methodology and transparent process to present an accurate picture of existing dementia care models within primary care. However, several limitations must be noted. During our scoping review, we limited our search to articles discussing impact on quality of life; we sought literature from only 11 Commonwealth countries; and, although French language articles were included, our search was limited to English databases. Finally, our grey literature search was not exhaustive, as we conducted a simple keyword search in the Google search engine only. Therefore, we must acknowledge that it is likely that we did not capture all existing models and resources. Review of literature from other countries, including non-Commonwealth countries, may identify other promising models of care and assessments of impact on quality of life for PLWD and their care partners. The models of care identified by the working group and the identified provincial and territorial strategies and programs were not evaluated for impact on quality of life or other outcomes. A more in-depth investigation into the reach, quality, equity, accessibility, and effectiveness of these models, strategies, and programs was beyond the scope of this review but is recognized as the necessary next step. In some provinces, such as Quebec, evaluation of such outcomes is underway; implementation of the Quebec Alzheimer Plan shows promise, with positive impact on detection and management of neurocognitive disorders (Godard-Sebillotte, Vedel, & Bergman,

2016; Vedel, Sourial, Arsenault-Lapierre, Godard-Sebillotte, & Bergman, 2019). A more fulsome analysis of the grey literature could also be done to identify unpublished or emerging innovations in dementia care. Additionally, follow-up interviews with the authors of the articles identified during the scoping review are recommended to assess the sustainability of the models/programs and other information pertinent to national spread.

Conclusion

Many models supporting primary care-based dementia care exist in the literature. Resources supporting PLWD and their care partners are available across most of Canada, although overarching strategies were found to be in place in only five provinces, suggesting a need for greater coordination. The models identified in our study are supported by evidence of positive outcomes, although evidence of their impact on quality of life for PLWD and their care partners was limited to a single study. Although these findings are encouraging, further research is needed to identify primary care models for dementia care that demonstrably improve quality of life. Given that primary care practices are complex adaptive systems, no single model fits the context of every practice. The evidence recommends that the core components identified be adapted to local needs, complexities, and resource constraints.

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