

Family Physician–Case Manager Collaboration and Needs of Patients With Dementia and Their Caregivers: A Systematic Mixed Studies Review

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ABSTRACT

PURPOSE Dementia case management (CM) in primary care is a complex intervention aimed at identifying the various needs of patients with dementia and their caregivers, as well as the organization and coordination of care. A key element of CM is the collaboration of family physicians with case managers. We conducted a systematic mixed-studies review to identify the needs of the patient-caregiver dyad and the effects of CM.

METHODS We searched MEDLINE, PsycINFO, and EMBASE up to October 2014, regardless of the study design. Our main outcomes were needs of patients and their caregivers and the effects of CM on these needs. We used narrative syntheses to develop a taxonomy of needs and to describe the effects of CM on those needs. We used meta-analysis to calculate the prevalence of needs and the standardized mean differences to evaluate the effects of CM on the needs identified.

RESULTS Fifty-four studies were included. We identified needs of the patient-caregiver dyad and needs of the patient and caregiver individually. CM addressed the majority of the identified needs. Still, some very common needs (eg, early diagnosis) are overlooked while other needs (eg, education on the disease) are well addressed. Fully establishing the value of CM is difficult given the small number of studies of CM in primary care.

CONCLUSIONS There is good evidence that case managers, in collaboration with family physicians, have a pivotal role in addressing the needs of the patient-caregiver dyad.

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INTRODUCTION

The proportion of people with dementia is growing dramatically. According to the US Alzheimer's Association, by 2030, 50% of Americans aged 65 years and older will be diagnosed with dementia.¹ In Canada in 2011, 747,000 Canadians lived with cognitive impairment.² Today, the combined costs are \$33 billion per year,¹ and they are projected to increase to \$872 billion by 2038.^{3,4} Worldwide, dementia is the main contributor to disability-adjusted life years (11.2%), representing a greater burden than cerebral vascular accident (9.5%), heart disease (5.0%), or cancer (2.4%).⁵

People with dementia need help with challenging changes in behavior, memory, physical disability, and mood.⁶ The main source of help is family caregivers, who often suffer from the burdens of caregiving and from depression and health problems.⁷ It has been shown that early intervention makes the greatest difference in management of symptoms.¹ The World Health Organization states that it would be challenging to intervene without effective involvement of primary care.⁸ Dementia case management (CM) interventions are becoming a central component of primary health care organizations in North America and Europe.⁹⁻¹² According to the

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Case Management Society of America, case management is "a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources..."¹³ Case managers are health care professionals who provide follow-up, coordinate individual care, and liaise with other health care services. They work in collaboration with family physicians, specialists, or both.¹⁴⁻²²

Over the last few years, several systematic reviews have found that the evidence of CM's effects on service use and clinical outcomes is weak.²³⁻²⁸ None of them specifically focused on the needs of patients and caregivers, however.²³⁻²⁸ Patients with dementia and their caregivers who already receive professional care still report unmet needs.²⁹ Moreover, they feel that their own opinion is not taken into account.³⁰ In line with the patient-centered care paradigm,^{31,32} it is important to identify the needs felt by the patient and the caregiver³³⁻³⁵ and to determine the extent to which CM interventions respond to their needs.³⁶

We conducted a systematic review to answer the following research question: Does the collaboration of family physicians with case managers respond to the needs of patients with dementia and their caregivers living in the community?

METHODS

We conducted a systematic mixed-studies review by including studies with diverse designs (quantitative, qualitative, and mixed methods).³⁷ This type of review has been deemed appropriate for the study of complex interventions.³⁸ It overcomes the issue of a partial picture that results from relying on a single type of research in isolation, assists in the critical analysis of interventions from the viewpoint of participants targeted,³⁹ and enables a single review to answer a number of questions (eg, identifying needs and evaluating how well they have been met).⁴⁰ It produces research more useful for decision makers and maximizes the use of review results (maximizes the conversion of knowledge to action) by enhancing their utility and impact.³⁹

Inclusion Criteria

To be included in our review, studies had to meet the following criteria:

- They had to deal with community-dwelling patients of any age with any type of dementia and/or their informal caregivers.
- They had to concern collaboration between a family physician and a case manager that comprises a comprehensive needs and health assessment, planning

of services and their coordination, monitoring, and regular proactive follow-up.^{13,41}

- They had to focus on primary medical care, defined as a range of community settings where family physicians intervene (patients' homes and offices).⁴²
- They could be of any type or design.
- Their outcomes could be the effects of CM on any type of need expressed by patients, expressed by caregivers, or measured.

Search Strategy and Study Selection

In accordance with PRISMA statement standards,⁴³ a literature search was conducted by a specialized librarian; publications in English, French, or Russian listed in MEDLINE, PsycINFO, or EMBASE, published before October 2014, were searched (Supplemental Appendix 1, available at <http://annfammed.org/content/14/2/166/suppl/DC1>). Given the objectives of our review, 2 search strategies were applied in parallel: 1) studies of the needs of community-dwelling patients with dementia and their caregivers, and 2) studies of CM (Supplemental Figure, available at <http://annfammed.org/content/14/2/166/suppl/DC1>). Based on the eligibility criteria, relevant titles, abstracts, and full-text articles were selected independently by 1 author (V.K.) and a research assistant (Martin Beauchamp).

Quality Assessment

The quality of the studies was assessed independently by 1 author (V.K.) and one outside reviewer (Quan Nha Hong, MSc) using the validated Mixed Methods Appraisal Tool designed for the critical appraisal of studies with diverse designs.⁴⁴⁻⁴⁶ Studies were scored on their internal and external validity (eg, representativeness of the sample, randomization). Studies were included without regard to their quality. We performed a sensitivity analysis (with a potential score of 0 or 1) to assess the impact of lower-quality studies on the results.

Data Extraction and Synthesis

Two reviewers (V.K. and Beauchamp) independently extracted and coded data; discrepancies were resolved through consensus. We used a 3-step approach to synthesize the findings:

1. We defined a need as a perceived state of deprivation communicated by patients or their caregivers.⁶ The prevalence was extracted if it was reported. Needs expressed in other domains measured by instruments were also searched (eg, domains of quality of life).⁶ We used a narrative synthesis approach to develop a taxonomy of the needs and meta-analysis to evaluate their prevalence.
2. A narrative synthesis approach was applied to describe the key components of CM.

3. A narrative synthesis was used to describe CM effects on the needs (mapping of CM components to the needs identified in Step 1) and a meta-analysis to estimate their effects.

Narrative synthesis was the main analytical approach we used, while meta-analyses were performed to explore the observed effects (Table 1).

RESULTS

Fifty-four studies were included in the review: 46 on the needs of patients and their caregivers⁵²⁻⁹⁸ and 8 on CM (Supplemental Figure, available at <http://annfammed.org/content/14/2/166/suppl/DC1>). The characteristics of the included studies are presented in Table 2, and Supplemental Appendixes 2 and 3, available at <http://annfammed.org/content/14/2/166/suppl/DC1>.

Identification of Needs

Three main categories of need were identified and are presented in Table 3: needs of the patient-caregiver dyad, needs of the patient, and needs of the caregiver. Many needs are common to patients and caregivers. The needs reported by the largest number of studies are needs of the dyad: for education or counseling on the disease (32 studies) and early diagnosis (13 studies).

Meta-analyses showed that 58% (95% CI, 43%-72%) of caregivers were in favor of early dementia

diagnosis, 50% (95% CI, 35%-65%) were in need of education on the disease, and 23% (95% CI, 17%-31%) needed in-home support (Table 4). Needs for meaningful activities that patients could participate in and assistance with daily activities were reported by 36% (95% CI, 5%-85%) and 22% (95% CI, 5%-59%) of patients with dementia respectively.

Description of Care Management

A key component of CM apparent in the studies we examined was close collaboration between case managers and family physicians (Supplemental Appendix 3, available at <http://annfammed.org/content/14/2/166/suppl/DC1>). The case managers involved were nurses specialized in care of the elderly.^{14-18,20} They were responsible for the coordination of treatment plans and for providing services. Through phone calls, web-based interactions, and case discussions, case managers communicated regularly with family physicians to inform them about patient and caregiver health conditions and needs.¹⁴⁻²² The role of family physicians was to develop care plans, provide medical treatment, and to modify care plans based on updates from case managers.

We mapped the components of CM to the needs identified from the perspectives of the patients and their caregivers (Table 5). To meet the needs of the patient-caregiver dyad, case managers performed the prediagnostic work-up to assist family physicians with

Table 1. Description of Synthesis

Step 1. Identification of the needs by narrative synthesis and meta-analysis

Narrative synthesis (main approach)	Through a narrative synthesis, we developed an integrated interpretation of various primary studies from which conclusions may be drawn. ⁴⁷ This synthesis provides qualitative rather than quantitative data. ⁴⁸ We followed a narrative approach that includes textual description of studies on needs of the patient and caregiver, extraction of the needs and their grouping into categories based on their common features (eg, education on disease), and then transforming data into common rubrics (taxonomy development). ³⁷ We divided the identified needs into 3 categories: needs of the patient, needs of the caregiver, and needs common to both (needs of the dyad).
Meta-analysis	We performed a meta-analysis on quantitative studies only to determine the prevalence of the needs identified. Starting with the prevalence proportions extracted from each study, we used R 3.1.2 (The R Foundation) to calculate the pooled prevalence proportion and 95% confidence interval for each need. ⁴⁹ We employed random-effects models, since the studies were statistically and methodologically heterogeneous. The I^2 statistic was used to measure heterogeneity. Considering the context (needs are generally evaluated in the observational studies) the meta-analysis included studies of different designs (eg, nonrandomized studies and surveys). ⁵⁰

Step 2. Description of case management

Narrative description	We described the main features of CM according to the definition of the Case Management Society of America, ¹³ then mapped the various components of CM to the needs identified in Step 1 that they targeted.
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Step 3. Evaluation of case management effects by narrative synthesis and meta-analysis

Narrative synthesis (main approach)	We followed the same narrative synthesis approach as in Step 1 to develop a textual description of the effects of CM on the subcategories of needs: mapping the components of CM to the needs identified in Step 1 from the perspectives of the patients and their caregivers. ³⁷
Meta-analysis	We then conducted a meta-analysis to explore the potential effects of CM on the identified needs where data were available. At this point, we included only randomized controlled trials at 12 months follow-up. Meta-analyses were conducted on the effects of CM on needs (eg, the need for confidence in caregiving) and on surrogate markers of needs (eg, behavior management as a surrogate for behavior disturbance of the patient and emotional support as a surrogate for depression and burden of the caregiver). To evaluate the intervention effect, we calculated the standardized mean differences between groups along with 95% confidence intervals, since different scales were used to measure the same outcome. To obtain missing data, we contacted the authors. Fixed-effects models were used because of the small sample size (2 in each outcome evaluation). ^{50,51}

CM = case management.

Table 2. Summary Characteristics of Included Studies

Characteristics	Description	
	Studies of Needs	Studies of CM
Continent/country:		
Americas, (16 studies)	USA ^{61,62,66,73,74,76,81,85,91,93,95,97} Canada ⁸⁴	USA ¹⁴⁻¹⁶
Europe (21 studies)	UK ^{20,52,53,64,69,72,77,78,83,84,99} The Netherlands ^{17,19,54,75,79,86} Sweden ^{21,22,70} Norway ⁹⁷ Italy ⁸⁵	UK ²⁰ The Netherlands ^{17,19} Sweden ^{21,22} Belgium ¹⁸
Oceania (5 studies)	Australia ^{65,67,88,98} New Zealand ⁷¹	...
Asia (7 studies)	China ⁶⁸ Hong Kong ^{90,96} Singapore ⁵⁹ Japan ⁸² Pakistan ⁵⁷ Turkey ⁵⁸	...
Africa (1 study)	Tanzania ⁵⁵	...
Multiple countries (3 studies)	UK – Poland ⁸⁷ USA – Canada ⁵⁶ Germany – UK – France – Poland – Spain – Luxembourg ⁹⁴	...
Type of studies	12 NRS ⁷⁴⁻⁸⁶ 11 quantitative descriptive studies ⁸⁷⁻⁹⁷ 22 qualitative studies ⁵²⁻⁷³ 1 mixed methods study ⁹⁸	5 RCTs ^{14,16-19} 2 NRS ^{15,20} 1 quantitative descriptive study ^{21,22}
Demographic characteristics of participants		
Age of patients (caregivers), mean, y	77 (58)	79 (61)
Type of dementia ^a		
Alzheimer's disease, %	59.8	57.6
Vascular dementia, %	14.0	17.0
Early onset of dementia	3 studies ^{53,54,88}	
Frontotemporal dementia	2 studies ^{56,89}	
Severity of dementia	Mild to moderate	Mild to moderate

CM = case management; NRS = nonrandomized studies; RCT = randomized controlled trial.

^a All studies concerned mild-to-moderate dementia. Percentages given are percentages of patients in pooled study populations.

diagnosis.^{21,22} They provided education on the disease, prognosis, treatment,^{16,17,19,21,22} and problematic home situations.¹⁸ They counseled on available resources/services,^{16,20} legal and financial issues, and advance directives.¹⁴⁻¹⁶ Finally, case managers coordinated medical and community services via electronic, written, and case conference discussion.^{14-17,19,20}

To meet the needs of patients, case managers applied, in collaboration with family physicians, non-pharmacologic and pharmacologic protocols for management of daily activities,¹⁴⁻¹⁶ behavior distress,^{14-16,21,22} cognition,¹⁴⁻¹⁶ mood,¹⁴⁻¹⁶ and home safety.^{16,18,19}

To meet the needs of caregivers, case managers provided support sessions and non-pharmacologic interventions for stress management^{14,15,17} and coping skills.¹⁴ They also developed care plans^{14-18,20-22} and coordinated home care services¹⁶⁻¹⁸ and social services.^{16,17,21,22}

Evaluation of the Effects of Care Management

CM was able to address almost all identified needs (Table 5). The number of diagnoses made by family physicians working with case managers increased while the rate of diagnosis by specialists without case managers remained stable.^{21,22} CM led to better education on the disease^{15,16,20} and provision of sufficient information on dementia-specific community resources.^{15,20} No effect on the understanding of medical treatment and knowledge of dementia was shown in 1 study, however.¹⁶ CM proved to establish good coordination of health care services, continuity, and quality of care,¹⁴⁻¹⁷ except in 1 study.¹⁸

CM also better addressed the needs of patients. More patients received non-pharmacologic behavioral protocols.¹⁶ Acetylcholinesterase inhibitors were more frequently prescribed by family physicians working with case managers, while neuroleptics prescription decreased.^{21,22} More patients were enrolled in the Safe Return program.¹⁶

CM also showed effects on the needs of caregivers. Caregivers' confidence with care increased.¹⁶

Their decision-making capacity improved,^{15,16} as did satisfaction with social support,¹⁶ and in-home help (eg, cleaning services).^{16,17} Moreover, caregivers were actively involved in care-plan development and regular discussion of the patient's health problems.^{16,17}

The effects on the needs for early diagnosis, financial and legal aspects of the disease, and meaningful activities were not studied. CM was not found to have any effect on patients' daily activities, cognition and depression.

A meta-analysis of the effects of CM (Figure 1 and Supplemental Appendix 4, available at <http://>

annfammed.org/content/14/2/166/suppl/DC1) showed a significant decrease in behavioral disturbance of patients as a result of psychosocial interventions along with acetylcholinesterase inhibitors (standardized mean difference [SMD] -0.27, 95% CI, -0.53 to -0.01, $P = .04$)^{14,17} and a significant increase of confidence in caregiving (SMD 0.19, 95% CI, 0.01-0.37, $P = .04$) due to the education in coping skills.^{16,17} The effect on depression of caregivers was uncertain (SMD -0.23, 95% CI, -0.46 to 0.01, $P = .06$),^{14,17,18} and there was no

effect on caregivers' burden (SMD 0.17, 95% CI, -0.18 to 0.52, $P = .34$).

Quality of Evidence

Almost all studies (43 studies) of the needs of the dyad and all 8 studies of CM proved to be of high quality. The majority of RCTs clearly described the randomization, blinding, and drop-out rate. Most non-randomized and quantitative descriptive studies (surveys) reported adequate sampling strategies and measurements.

Table 3. Needs of Community Dwelling Patients With Dementia and Their Caregivers

Categories of Need	Description	No. of Studies
Needs of the patient/caregiver dyad		
Early diagnosis ^{52-54,56,64-66,73,80,85,87-89}	Need for early diagnosis (to understand the behavioral problems and gain timely access to resources).	13
Education/ counseling ^{54-52,59-68,72-75,79,80,82,85-89,92-97}	Need for specific information on medical and interpersonal aspects of the disease, meaningful counseling on dealing with behavioral problems, guidelines on dementia before and after diagnosis.	32
Information about relevant services ^{65,74,75,82,83,85,89,92,94,96,98}	Need for an overview of available formal care services such as community psychiatric services, domestic help, caregivers' support groups, and insurance.	11
Legal assistance ^{66,85,93,97}	Need for assistance with legal documents and advice on guardianship, power of attorney, etc.	4
Financial support/ planning ^{53,55,57,59,66,68,88,89,92,93,96,97}	Need for assistance with access to financial programs that can help if the caregiver quits a job to take care of the patient and help deal with household and medication expenses.	11
Advance care planning ⁸⁵	Need for information on future care problems.	1
Care coordination/continuity of care/well-defined care pathway ^{52-54,64,65,67,68,73,86,98}	Need for continuity between the various health care services involved, access to services corresponding to the severity of the disease, support throughout the course of the disease from the same health care professionals, and coordination of medical and community services to optimize services and prevent overlap.	10
Access to family physicians trained in geriatrics ^{52-54,66,86,88,92}	Need for access to a family physician who has adequate knowledge of the disease, is sensitive to the concerns of patient and caregiver, can provide guidance on dementia, and can follow patients with dementia and their caregivers.	7
Access to other health care professionals trained in geriatrics ^{65,70,73,81,86-88}	Need for access to health care professionals who know the disease, respond competently at disclosure of the diagnosis, and communicate test results clearly.	7
Needs of the patient		
Meaningful activities ^{60,74,77-79,84,85,90,95}	Need to take part in activities, join in with others, do things, and have company.	9
Assistance with ADL/IADL ^{57,68,74,76,79,84,85,87,88,91,97}	Need for help with ADL (commonly for bathing/dental care, dressing, and walking) and with IADL (commonly for housekeeping, meal preparation, and transportation).	11
Behavior management ^{63,75,84,87,88,90,91,95,97}	Need for pharmacologic and nonpharmacologic approaches to managing the behavioral spectrum of the disease, especially agitation and restlessness, verbal aggression, and anxiety.	9
Cognition management ^{79,84,87,88,90}	Need for pharmacologic and nonpharmacologic approaches to managing the cognitive spectrum of the disease.	5
Management of mood swings/ depression ^{77-79,84,90,93,97}	Need for pharmacologic and nonpharmacologic approaches to managing depression.	7
Safety ^{69,74,77,78,84,85,91,97}	Need for help in managing fall and wander risk, ensuring home safety, and minimizing the risk of accidental self-harm.	8
Needs of the caregiver		
Emotional support ^{53,57,59,62-64,74,80,95,97}	Need for assistance with feelings of being alone, abandoned, helpless, exhausted, and mentally burdened.	10
Social support ^{53,56,58,59,62,67,75,81,87,88,91,97}	Needs to have social outlets such as time alone, social interaction with friends, opportunities to shop and to go out.	12
In-home support ^{55,58,66,75,83,95}	Need for help with house chores (eg, cleaning).	6
Capacity to provide care ^{62,63,80,87,89,90,96,97}	Need for training in communication skills and in strategies for handling maladaptive behaviors and.	8
Involvement in care planning ⁶⁵	Need to be included as an equal partner in formal and informal care planning.	1

ADL = activities of daily living; IADL = instrumental activities of daily living.

Note: Needs for help with urinary incontinence,^{66,84} help with sight and hearing problems,^{77,78,97} and culturally sensitive services⁶¹ are not presented in the table, since only a few studies evaluated these needs.

Table 4. Meta-Analysis of Needs of Patients and Their Caregivers

Categories of Need	No. of Studies	Pooled Proportion (95% CI)	Variation Across Studies (I ² , %)	Test of Heterogeneity (Q ²), P value
Needs of the patient-caregiver dyad ^a				
Early diagnosis ^{80,88,89}	3	0.58 (0.43-0.72)	80.0	.007
Education/counseling on disease ^{79,80,82,89,92,94-96}	8	0.50 (0.35-0.65)	97.3	<0.001
Needs of the patient ^b				
Meaningful activities ^{74,79,85}	3	0.36 (0.05-0.85)	97.8	<0.001
Assistance with ADL/IADL ^{74,79,85}	3	0.22 (0.05-0.59)	95.5	<0.001
Needs of the caregiver ^a				
In-home support ^{75,83,95}	3	0.23 (0.17-0.31)	17.7	0.30

ADL = activities of daily living; IADL = instrumental activities of daily living

^a Needs reported by caregivers.

^b Needs reported by patients.

Table 5. Mapping of Components of Case Management to Needs and Their Effects on the Needs

Categories of Need	Corresponding Components of Case Management	Resultant Effects
Needs of the patient/caregiver dyad		
Early diagnosis ^a	Gathering information through the basic diagnostic battery to help family physicians establish a diagnosis ^{21,22}	Dementia diagnosis increased in primary care while remaining stable in specialty care ^{21,22}
Education/counseling on disease	Holding interactive seminars and family meetings for patients and caregivers on relevant care issues ^{16,17} Providing information by phone to caregivers ^{17,18} Helping the patient and family understand the disease, prognosis, and rationale of treatment ^{19,21,22} Exploring problematic home care situations ¹⁸	Caregivers understood medical treatment for behavior and depression: 78.4% vs 72.2% in usual care (P = .49) ⁶ Perception of caregiver's clarity in discussing patient's care: 16.8% vs 21.3% of usual care (P = .01) ¹⁶ 100% of caregivers were satisfied with the ability of case managers to answer questions ¹⁵ Educational material was relevant to the dyad situation in 95% of cases ¹⁵ 95% of caregivers were satisfied with quality of educational material provided ¹⁵ A majority of caregivers were satisfied with information allowing them to understand the nature of the disease ²⁰ Caregiver knowledge about dementia was not improved (P = .19) ¹⁶
Information on relevant services	Recommending caregiver resources—eg, Alzheimer's Association, meals on wheels, and Safe Return program (for wandering) ¹⁶ Helping with various services (day care, respite care) ²⁰	97% of caregivers were satisfied with the information they received on community resources ¹⁵ Caregivers were more aware of dementia-specific resources ²⁰
Help with legal issues	Educating caregivers on legal issues ^{14,15}	Not evaluated
Financial support and planning	Educating caregivers on dementia-related financial planning ¹⁴⁻¹⁶	Not evaluated
Advance care planning	Advising on advance directives ¹⁶ Interactive seminars for caregivers on evaluation of decision-making capacity ¹⁶	With CM, advance directives were discussed or completed and documented in 69.4% of cases, vs 44.4% in usual care (P = .001) ¹⁶ Decision-making capacity improved in 34.2% of patients vs 9.7% in usual care (P = .001) ¹⁶ 90% of caregivers were satisfied with future planning ¹⁵
Care coordination, continuity of care, and a well-defined care pathway	Communicating regularly with family physicians, ^{14,15,17,19} maintaining written consultation notes, ^{14,16} producing secure electronic updates, ¹⁵ via web-based systems, ^{14,16} and attending case conferences ^{14,20} Connecting patients and their caregivers to support services ^{16,17,19} Operating in conjunction with any services patient already had ²⁰	70% to 82.8% of caregivers rated a new way of primary care delivery as very good/excellent ¹⁴ 88% of caregivers were satisfied with the care coordination provided ¹⁷ 100% of caregivers stated that intervention was efficient ¹⁷ 95% of caregivers were satisfied with the ability of case managers to link them with community resources ¹⁵ The quality of patient's health care improved (P = .003) ¹⁶ 1 study found no difference in interdisciplinary communication between intervention and usual care group (P = .5) ⁸

continues

Table 5. Mapping of Components of Case Management to Needs and Their Effects on the Needs (continued)

Categories of Need	Corresponding Components of Case Management	Resultant Effects
Access to health care professionals trained in geriatrics	Case managers are trained in geriatrics/geropsychiatry, ^{14-18,20} communicating the diagnosis to the families, ¹⁴ skills in communicating with patients and their caregivers, ¹⁷ dementia home care ¹⁸ Involving a multidisciplinary team in patient care (eg, geriatrician, geriatric psychiatrist, and psychologist) ¹⁴ Helping with access to health care professionals ¹⁹ Referring to specialists if needed ^{17,21,22}	Not evaluated
Access to family physician trained in geriatrics	No prior formal training of family physicians in geriatrics	Not evaluated
Needs of the patient		
Meaningful activities	Providing patient exercise guidelines and resources (eg, group chair-based exercises) ^{14,15}	Not evaluated
Assistance with ADL/IADL	Advising on implementation of predictable routine of daily activities ¹⁹ Providing nonpharmacologic protocols that include mobility management, personal care concerns ^{14,15}	No effect ^{14,18}
Behavior management	Arranging interactive seminars for caregivers on evaluation of acute behavior changes ¹⁶ Providing specific protocols and nonpharmacologic interventions for repetitive behavior, agitation, aggression, delusions or hallucinations ¹⁴⁻¹⁶ Providing drug therapy with anticholinesterase inhibitors and memantine ^{14,16,21,22}	47.2% Received as much help as needed with behavioral problems vs 29% in usual care ($P = .01$) ¹⁶ The rate of antidementia medication prescription by family physicians was increased from 42% to 86% and the rate of neuroleptic prescription decreased ^{21,22}
Cognition management	Assessing patients' memory regularly ¹⁴⁻¹⁶ Educating on communication ¹⁴ and applying nonpharmacologic protocols that include communication techniques ¹⁵	No effect ¹⁴
Management of mood swings/depression	Providing a specific protocol of nonpharmacologic interventions on depression, with drug therapy as a backup ^{14,15} Arranging interactive seminars for caregivers on managing depression in patients ¹⁶	No effect ^{14,18}
Safety	Making recommendations on home safety and the Safe Return program (for wandering) ¹⁶ Providing personal alarms ¹⁸ Assessing the patient's home situation ¹⁹ Guiding the caregiver in organizing home care ¹⁸	27.3% of patients were enrolled in Safe Return vs 8.4% in usual care ($P = .001$) ¹⁶
Needs of the caregiver		
Emotional support	Providing support sessions focused on caregiver stress ^{14,17} ; Recommending nonpharmacologic protocols that includes stress management ¹⁵	In 2 studies, caregiver mood improved at 12 months ($P = .03$) ^{14,18} ; another found no effect at 18 months ($P = .33$) ¹⁴ Caregiver burden was not affected ($P = .49$) ^{17,18}
Social support	Recommending a caregiver support group ¹⁶ ; Organizing family meetings aimed at improving social support and relieving the primary caregiver ^{17,21,22}	Caregivers' support systems were adequate in 80.4% of cases vs 45% in usual care ($P = .001$) ¹⁶ 40.7% of caregivers received services vs 19.2% in usual care ($P = .002$) ¹⁶ Caregivers were socially supported ($P = .03$) ¹⁶
In-home support	Helping with home care, ^{17,18} meals on wheels, ¹⁶ and dinner services ¹⁷	38.7% of caregivers received in-home help vs 28.9% in usual care ($P = .02$) ¹⁶ 100% of caregivers were satisfied with home help ¹⁷
Capacity to provide care	Educating caregivers on coping skills ¹⁴	Caregiver confidence and mastery were greater in CM ($P = .001$) ¹⁶
Involvement in care planning	Involving caregivers in individualized care plan and problem list development ^{14-18,20-22}	38.2% of caregivers were involved in care plan development vs 22.1% in usual care ($P = .001$) ¹⁶ In 82.5% of cases, caregiver gave input on behavior issues vs 39% in usual care ($P = .001$) ¹⁶ 96% of caregivers were satisfied with discussion of patient's health problems ¹⁷

ADL = activities of daily life; CM = case management; IADL = instrumental activities of daily living

^a Only 1 of the studies on CM interventions enrolled patients not already diagnosed with dementia.²¹

Qualitative studies clearly described their inclusion and exclusion criteria, methods of analysis, and contexts. Exclusion of studies of lower quality did not change the overall results (Supplemental Appendix 5, available at <http://annfammed.org/content/14/2/166/suppl/DC1>).

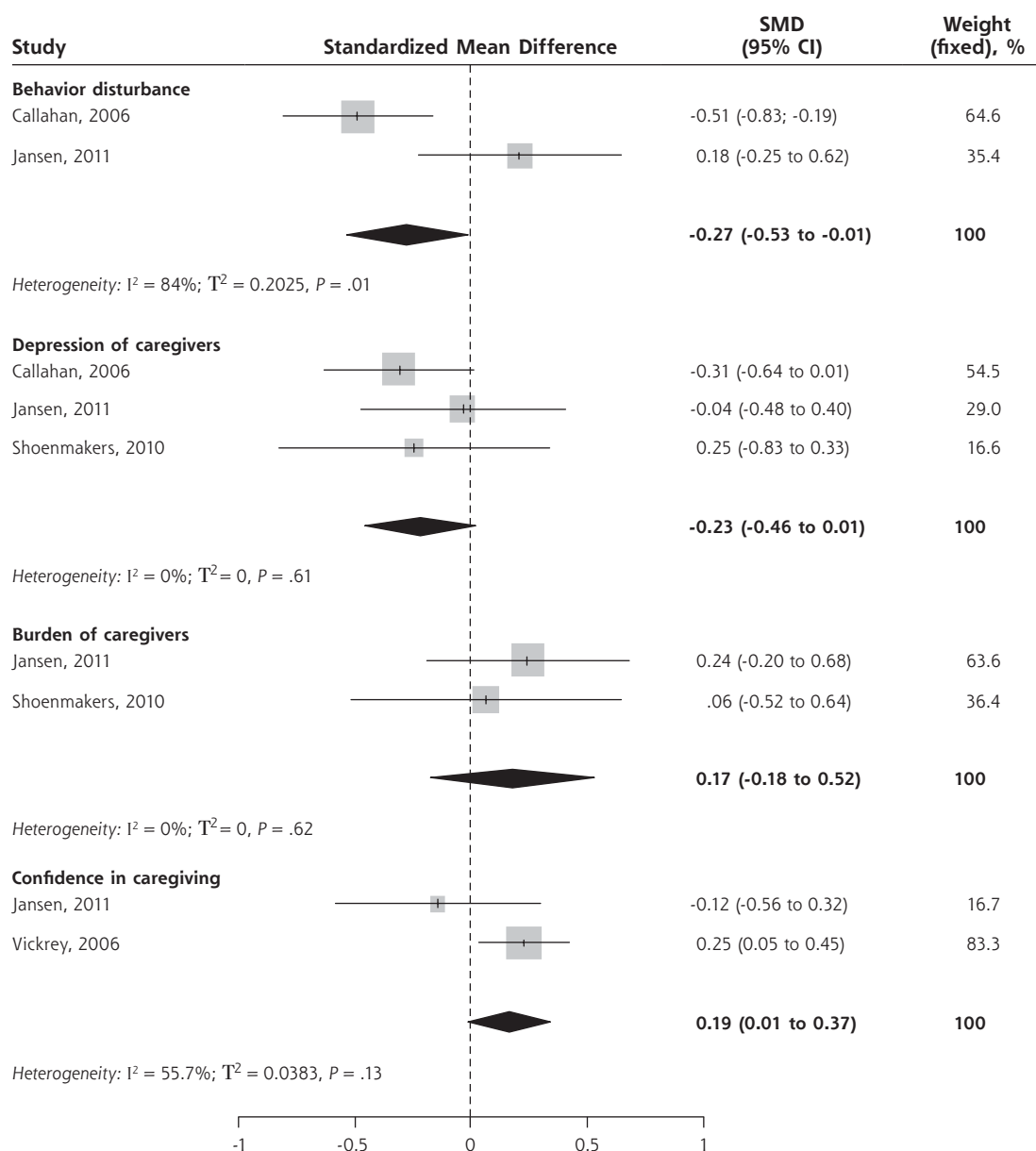
DISCUSSION

This is the first systematic mixed-studies review conducted to evaluate whether CM meets the needs of patients with dementia and their caregivers. The main novelty of our review is that we first identified the

needs from the perspectives of patients and their caregivers and only then evaluated whether CM targeted their needs and led to the desired outcomes. Our systematic review showed that CM addressed most needs of patients and caregivers. It also demonstrated that some very common needs (eg, early diagnosis) are still overlooked, while other needs (eg, education/information) are well targeted.

The most frequently reported need was early diagnosis of dementia. The impact of CM on this important need, however, has not been evaluated. While there is no consensus among health care profes-

Figure 1. Forest plot of standardized mean differences of case management vs control by subgroups.



sionals on the early diagnosis of dementia,¹⁰⁰⁻¹⁰³ our systematic review suggests that patients and their caregivers would like to receive an early diagnosis. Early diagnosis of dementia does not necessarily change the disease's course,¹⁰⁴ but it prompts health care professionals to identify the needs earlier and thus sustain the quality of life for both the patient and the caregiver.¹⁰⁵ Moreover, it may positively affect appropriate medication prescription, decrease levels of caregiver burden and depression, and diminish the risk of early placement in a long-term care facility.^{106,107}

The second most frequently reported need was education and counseling on the disease. This finding is in line with those of previous research, which has showed that most unmet needs were related to a lack of knowledge about the existing services, progression of dementia, and management of behavioral problems.^{29,79,108,109} Unlike early diagnosis, this need seems to be well targeted and appropriately addressed by CM.

Identification of the needs of patients and their caregivers is the basis for the development of interventions sensitive to these needs.⁶ CM focuses on integration of medical and community services to deliver patient-centered care according to the specific needs of individual patients.¹³ The key element of CM is the collaboration of case managers with family physicians. Regular communication between case managers and family physicians is essential to the patient-centered care targeting these vulnerable populations; it allows family physicians to make timely modifications of their care plans.

Formal training of case managers in care of the elderly is a valuable asset to the care.^{14-18,20} Case managers specialized in dementia care can assess needs promptly and follow up regularly. For instance, they are better able to evaluate the needs of patients with regards to daily activities and orient them to the appropriate services (eg, mobility improvement programs).¹⁴⁻¹⁶ They also assess the needs for information and support and guide the patient-caregiver dyad to the appropriate services (eg, the Alzheimer Society or the Alzheimer's Association).^{15,16,20} Moreover, as the first point of contact for the dyad, they appear to be more easily reachable than family physicians.^{14-18,20-22} Our previous studies demonstrated that the effectiveness of CM depends on a small caseload, regular and proactive follow-up, and transparent communication among health care professionals.^{110,111}

Limitations

As in any systematic review, we may have missed studies that we should have included. It is unlikely, however, that we missed large studies, as the literature search was comprehensive and included publications in

3 languages (English, French, and Russian). The meta-analysis of the effects of CM was conducted on a limited number of available studies, but it was exploratory; its conclusion should be considered with caution. The limited number of available studies on CM in which family physicians collaborate with case managers necessarily limited our review.

Future Research

Future studies are needed to evaluate the effects of CM on the needs that are overlooked—early diagnosis of dementia, legal issues, and financial issues. An avenue for some future studies could be the integration of social workers into primary care to assist with financial and legal issues of the dyad.¹⁶ Family physicians and researchers should perceive the needs of the dyad as unique features of patient-centered outcomes research related to primary care.

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Key words: case management; dementia, primary care; collaborative care; patient-centered care; systematic review

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