Management of dementia by family physicians in academic settings

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ABSTRACT

OBJECTIVE To determine what proportion of patients with dementia seen by family physicians are assessed and managed according to the recommendations of the Canadian Consensus Conference on Dementia (CCCD).

DESIGN Retrospective medical record review.

SETTING Outpatient services in university-affiliated family practice clinics in Calgary, Alta; Ottawa, Ont; and Toronto, Ont.

PARTICIPANTS One hundred sixty patients who were diagnosed with dementia between January 1, 2000, and June 1, 2004.

MAIN OUTCOME MEASURES Use of the Mini-Mental State Examination (MMSE); collateral history; physical examination maneuvers; initial laboratory tests; diagnostic imaging; caregiver identification, assessment, and referral; driving assessment; specialist referral patterns; and other recommendations of the CCCD.

RESULTS The average age of patients assessed was 83 years; most patients (66.3%) were female. More than half (54.1%) were diagnosed with Alzheimer disease or vascular dementia. More than 25% of patients were not given a specific diagnosis: 13.1% were labeled as "dementia," and 12.5% as "not yet diagnosed." For most patients (69.6%) a collateral history was obtained and a primary caregiver identified (79.4%). Few physicians, however, assessed caregiver stress (33.1%) or referred caregivers for support (12.5%). Most patients (80.6%) seen by their family physicians for cognitive changes underwent at least one MMSE. The average score on the first MMSE was 23.5 (of 30) points. Most physicians ordered appropriate "basic" blood tests as part of their assessment. Forty percent of patients had computed tomographic examinations within 3 months of reporting symptoms of cognitive difficulties to their family physicians. Of these, 25% met the criteria for computed tomographic scan as recommended by the guidelines. Only 36.5% were asked about driving status or safety concerns and had this inquiry documented. Of those, 15.5% were referred for driving evaluations and 12.5% were reported to the Ministry of Transportation.

CONCLUSION There is fair to good compliance with recommendations of the 1999 CCCD guidelines. There is, however, little assessment of caregiver coping and referral of caregivers for support. Similarly, there is little assessment of driver safety and referral for formal driving evaluations. Computed tomographic imaging as part of the evaluation of dementia is overused.

EDITOR'S KEY POINTS

- By 2031, it is predicted that the average family physician will have 4 to 8 new patients developing dementia yearly.
- This study assesses the extent to which family physicians follow the 1999 CCCD guidelines' key recommendations on evaluating people suspected of having dementia.
- Serum calcium was underordered, and 15% of patients who had computed tomography did not meet the CCCD criteria for neuroimaging. Caregiver coping was assessed infrequently. Few patients were assessed for driving ability, although driving safety is a concern in dementia.

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Dementia affects about 8% of all people older than 65 and between 3% to 6% of people older than 65 who still live in their communities.[1,2] The prevalence of dementia increases with advancing age and is more common among elderly patients in primary care settings, hospitals, or nursing homes.[2-5]

Almost 400 000 elderly Canadians have dementia. Experts predict this number will reach 750 000 by the year 2031.[1] These figures suggest the average family physician will have 20 to 40 patients with dementia in his or her practice and 4 to 8 new patients developing dementia each year.

In 1989 the Canadian Consensus Conference on Dementia (CCCD) developed guidelines for evaluating people suspected of having dementia.[6] These guidelines were updated in 1999[7,8] and included 48 recommendations addressing the following aspects of dementia care: early recognition; importance of careful history and examination in making a positive diagnosis; essential laboratory tests; rules for neuroimaging and referral; disclosure of diagnosis; importance of monitoring and providing support to caregivers; detection and treatment of depression; observation and management of behavioural disturbances; detection and reporting of unsafe motor vehicle driving; genetic factors and opportunities for preventing dementia; and pharmacologic treatment with particular emphasis on cognition-enhancing medications.

The guidelines emphasize the importance of taking a complete history in assessment of dementia, and particularly the importance of collateral history. They emphasize the importance of assessing caregiver coping and referring caregivers for support. The guidelines recommend a panel of basic laboratory tests as part of initial investigation of cognitive impairment. These include a complete blood count, sensitive thyroid-stimulating hormone, serum electrolytes, serum calcium, and glucose measurements. A long list of "optional" investigations is recommended if clinical circumstances dictate.

The guidelines recommend neuroimaging (most commonly computed tomography [CT]) only if certain criteria are met. These include age younger than 60, rapid (ie, over 1 to 2 months) unexplained decline in cognition or function, "short" duration of dementia (less than 2 years), and recent and serious head trauma.

The guidelines also recommend that physicians assess driving safety for all patients presenting with cognitive impairment or dementia. They recommend that, if problems are identified, patients be referred for a formal driving assessment and, if indicated, that they be reported to the Ministry of Transport.

The purpose of this study was to assess the extent to which family physicians follow the guidelines' key recommendations.

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METHOD

Patients

All outpatients with a primary diagnosis of dementia (code 290 in the *International Classification of Diseases*, 9th revision) seen between January 1, 2000, and May 30, 2004, were identified from the billing records of participating family physicians in Calgary, Alta; Ottawa, Ont; and Toronto, Ont. Because we wanted to compare the practice patterns with the CCCD guidelines published in June 1999, we included only patients who received a diagnosis of dementia after January 1, 2001. Patients were excluded if they were younger than 65 years or were participants in a clinical trial for treatment of dementia.

We reviewed patients' charts from 3 family medicine clinics affiliated with the University of Calgary, 2 clinics affiliated with the University of Toronto, and 1 clinic affiliated with the University of Ottawa. For each physician at each clinic, a list of all eligible patients was generated. A random sample of 40 charts from the 3 Calgary clinics and from each of the other 3 clinics was audited for a total of 160 charts. Sample size was calculated using statistical techniques for descriptive studies with dichotomous variables. We expected 75% of the population to have undergone a Mini-Mental State Examination (MMSE) and to have it noted in their charts, believing that, for physicians to diagnose cognitive impairment, the MMSE would need to be performed for a minimum 75% of patients. We then based our sample size calculation on the proportion of patients who would not have taken the test (25%). We estimated the width of the 95% confidence interval to be 0.15. This yielded a minimum sample size of 128 charts.[9]

We collected data on the following items from the CCCD guidelines: patients' demographic characteristics and date of diagnosis of dementia; dates and scores of MMSE tests; general medical history and medications; assessment of basic activities of daily living (ADL) and instrumental ADLs; collateral history; assessment of reversible causes of dementia; physical examination including a complete neurologic and cardiovascular examination; basic laboratory tests; optional laboratory tests; cranial CT and the indications for ordering it; referral to specialists and criteria for referral; specialized drug therapy for dementia; assessment of driving; and assessment of caregivers' coping.

The study was approved by the research ethics boards of the University of Calgary, the Sisters of Charity of Ottawa Health Services, and Sunnybrook and Women's College Health Sciences Centre in Toronto.

Data collection

All study data were collected between June and September 2004 using an audit instrument developed and tested by the research team.

Data analysis

To preserve the anonymity of physicians and clinics, data were analyzed in aggregate and by group. Practice patterns in each group were described, and overall practice patterns were compared with the CCCD guidelines' recommendations.

Table 1. Demographic and clinical characteristics of patients assessed for dementia: *Mean age was 83.1 years.*

	PATIENTS ASSESSED	
CHARACTERISTICS OF PATIENTS	N	%
Female sex	106	66.3
Living arrangement at diagnosis		
• With spouse	53	33.1
• Alone	46	28.8
• Other	51	31.9
• Not documented	10	6.3
Education level		
• Elementary	11	6.9
• Secondary	24	15.0
• Post-secondary	18	11.3
• Postgraduate	9	5.6
• Not documented	98	61.3
Prior occupation		
• Professional	39	24.4
• Skilled trade	20	12.5
• Clerical	19	11.9
• Homemaker	14	8.8
• Not documented	68	42.5
Type of dementia		
• Alzheimer disease	61	39.1
• Vascular dementia	16	10.3
• Mixed Alzheimer disease and vascular dementia	8	5.1
• Lewy body dementia	3	1.9
• Frontotemporal dementia	3	1.9
• Unspecified dementia	21	13.5
• Mild cognitive impairment	17	10.9
• Not yet diagnosed	20	12.8
• Dementia ruled out	5	3.2
• Cognitive impairment due to medications	2	1.3

RESULTS

A total of 495 charts containing a diagnosis of dementia were identified. Of these, 160 were audited. The average age of patients was 83.1 years; most patients (66.3%) were female (**Table 1**). Education level and prior occupation were not documented in 61.3% and 42.5% of cases, respectively. Most patients were diagnosed with Alzheimer disease (39.1%); others were diagnosed with vascular dementia (10.3%) and mixed Alzheimer disease and vascular dementia (5.1%). These are the most common dementia diagnoses in the general population. A few patients were diagnosed with Lewy body dementia and frontotemporal dementia (3 patients for each). More than 25% of patients did not receive a specific diagnosis and were identified as having "dementia" (n = 21, 13.1%) or "not yet diagnosed" (n = 20, 12.5%) (ie, these terms were written in the chart). Only 2 patients were found to have a reversible cause of cognitive impairment; both causes were related to medications. There was a high burden of comorbidity in the sample, as shown in

Table 2. History taking and caregiver assessment

	PATIENTS	
ASSESSMENT	N	%
PATIENT AND FAMILY HISTORY		
Collateral history obtained	111	69.6
Collateral history obtained from:		
• Spouse	37	23.1
• Child	42	26.3
• Health care provider	16	10.0
• Other	18	11.3
CAREGIVER		
Caregiver identified	127	79.4
Caregiver coping assessed	53	33.1
Caregiver referral	21	13.1
BASIC ACTIVITIES OF DAILY LIVING AND INSTRUMENTAL ACTIVITIES OF DAILY LIVING		
Bathing	79	49.4
Dressing	82	51.3
Toileting	79	49.4
Transferring	75	46.9
Continence	83	51.9
Feeding	85	53.1
Shopping and banking	87	54.4
Housekeeping and meal preparation	83	51.9
Medication management	80	50.0

Figure 1. Cardiovascular risk factors, such as hypertension (55.6%), coronary artery disease (27.5%), and hypercholesterolemia (21.3%), were common.

Table 2 shows that, while a collateral history was obtained in 70% of cases and a primary caregiver was identified in 79.4%, caregiver coping was assessed in only 33.1% of cases. Caregivers were referred for support and assistance in only 13.1% of all cases.

We examined the extent to which family physicians ordered investigations (**Figure 2**). A good to very good number of physicians ordered the recommended "basic" tests, with the exception of serum calcium, which was ordered in only 35% of cases. With the exception of tests for serum creatinine (68.1%) and vitamin B_{12} (43.8%), few physicians ordered the so-called optional tests.

Just 40.6% of patients in the study had CT ordered within 3 months of reporting cognitive changes to a family physician. Only 25% of charts, however, had documented reasons that met the guidelines' criteria for CT. It is important to note that in many cases CT was ordered by consultants to whom patients had been referred and not by family physicians.

Rates of referral to specialists were high in our study. Twenty-three percent of patients were referred to geriatricians, 20.6% to geriatric psychiatrists, 30.7% to neurologists, and 7.5% to clinical psychologists. Overall, 82% of patients were referred.

In this study, only 36.5% of patients had a driving assessment documented in their records. Only 15.5% of all cases were referred for a formal driving assessment and only 12.5% of all cases were reported to the Ministry of Transport (**Table 3**).

Table 3. Assessment of driving

PATIENT ASSESSMENT	N	%
Patients asked about driving status	57	36.5
Patients referred for driving evaluation	25	15.5
Patients reported to Ministry of Transport	20	12.5

DISCUSSION

Results of this study show family physicians' compliance with the 1999 CCCD recommendations on assessment and management of dementia varies from poor to good, depending on which aspect of care is evaluated.

As with many other clinical practice guidelines, the CCCD used the criteria established by the Canadian Task Force on Preventive Health Care to assess the quality of evidence for each of 48 recommended maneuvers.[7] For A-level maneuvers (for which there is good evidence, such as from at least one properly randomized controlled trial) we could define "excellent" as 90% to 100% compliance with the recommendation and "poor" as less than 50% compliance. There are very few A-level maneuvers, however, in the CCCD guidelines. Most of the recommended maneuvers are B level, and many of these were based on expert opinion, not research data.

Figure 1. Comorbid illness

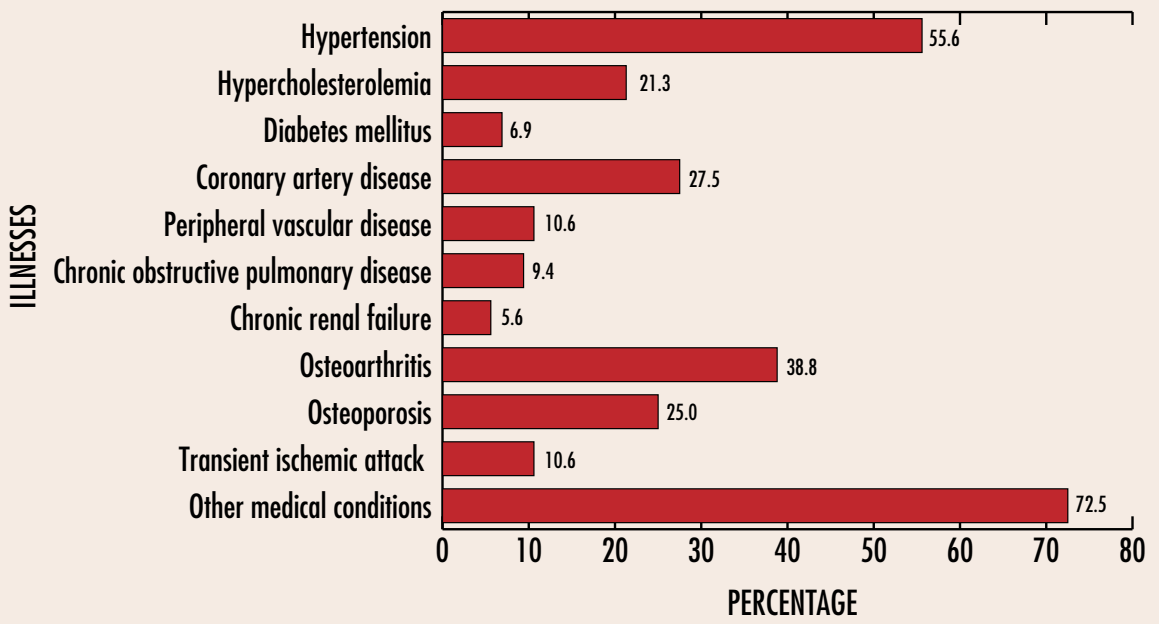
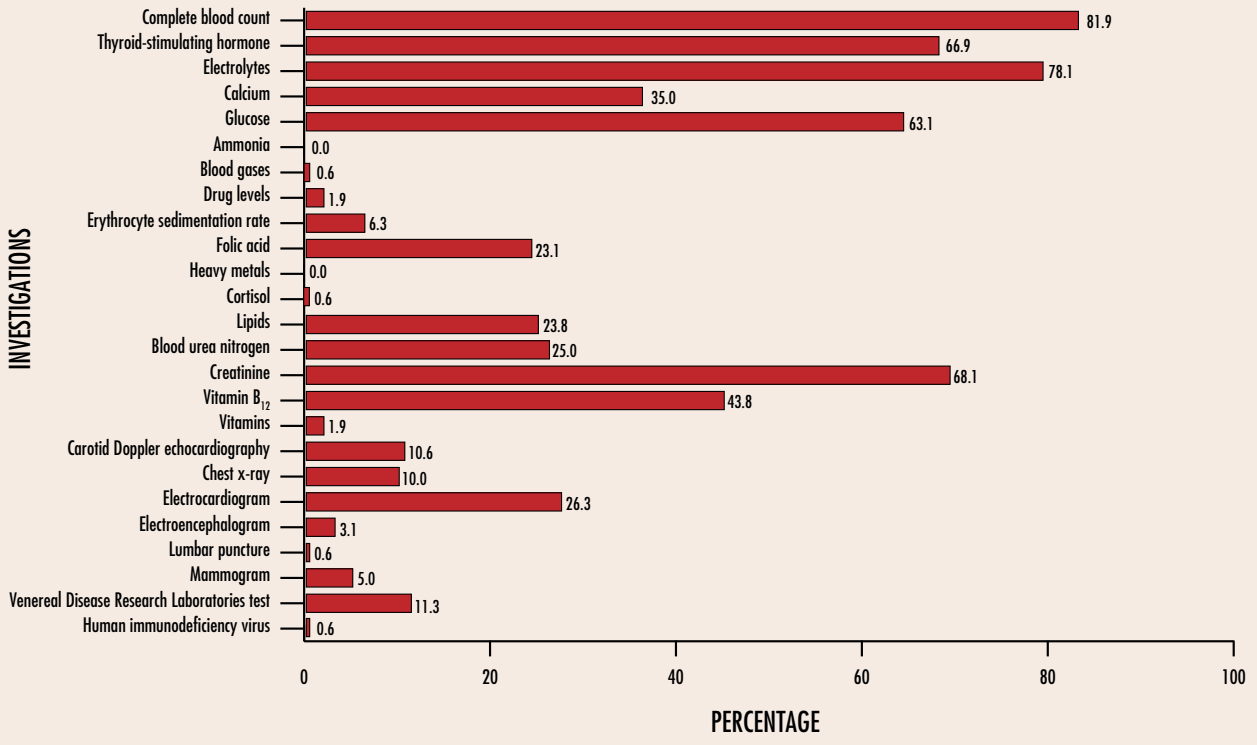


Figure 2. Investigations ordered



These included some of the key recommendations on use of the MMSE, basic laboratory tests, and referral. In light of this, it is difficult to characterize physicians' performance of these maneuvers.

Investigations

Obtaining a complete history, including a collateral history, is one of the key recommendations of the guidelines. For most patients, a spouse, child, health care provider, or other key informant provided a collateral history. More than 80% of patients underwent an MMSE within 3 months of presenting with cognitive changes. The guidelines recommend that physicians assess patients' ADL and instrumental ADL as part of the history. In this study, these were documented, on average, about 50% of the time. They were sometimes documented by family physicians, but often by another provider, such as a consultant, social worker, or home care provider.

Laboratory testing ordered by physicians was generally in keeping with the guidelines' recommendations. Recommended basic tests were ordered most of the time (ranging from 63% of cases for blood glucose to 82% of cases for a complete blood count) but, with the exception of serum creatinine and vitamin B_{12} levels, so-called optional tests were ordered infrequently. In the past, many physicians were taught that serum B_{12} and folic acid measurements should be ordered as part of a dementia workup, and this practice could account for the higher levels of B_{12} testing.

More than 40% of patients had CT as part of their assessment for cognitive impairment, but only 25% met the CCCD criteria for neuroimaging studies. The CCCD criteria have been evaluated in a retrospective study that examined their use in 200 consecutive patients attending a memory clinic.[10] Application of these criteria would have reduced the number of scans by nearly two thirds without changing clinical outcomes.

Areas of concern

This study reveals 2 areas of great concern in assessment of dementia by family physicians. First, while a caregiver was identified for most patients, caregiver coping was assessed in less than one third of caregivers. Second, only 13% of caregivers were referred for counseling or support. The CCCD guidelines have identified caregiver assessment as a priority for several reasons. Caregivers play a substantial, multifaceted role in care of people with dementia. Caregiver reports are as reliable as objective measures of cognitive decline and have a role in direct patient care. Absence of a caregiver is an important predictor of earlier institutionalization of people with dementia, and higher perceived caregiver burden leads to earlier institutionalization.[11] Up to 50% of caregivers develop psychiatric symptoms during the course of giving care.[12] There is evidence that a program

of counseling and support for caregivers can delay institutionalization.[13] In a systematic review of the literature, Cohen et al[14] identified caregiver assessment and support as a key role for primary care physicians.

Because the risk of motor vehicle collisions and fatal injury increases with the duration and severity of dementia,[15] the CCCD guidelines identify family physicians' assessment of driving ability as being very important. The guidelines acknowledge that it is difficult for physicians to assess patients' driving competence accurately in the office, except when dementia is so severe that increased driving risk is obvious. The guidelines therefore recommend performance-based assessment,[16,17] especially in cases of uncertainty. We are consequently concerned about the low level of assessment of driving status and safety in this study (36.5%), and about the very low level of referral for driver assessment (around 16%).

Guidelines are developed with the intent of changing and improving clinical practice.[18] The 1999 CCCD guidelines did not appear to change clinical practice after they were published. It is perhaps not surprising that this is the case.[19] First, only 32% of Canadian physicians reported that their practice had changed even once in the past year as a result of a set of guidelines.[20,21] Second, format and local applicability of a guideline are crucial to its successful implementation.[19] Clinicians consistently identify endorsement by a respected colleague or organization and guidelines' ease of use and clarity as the most important factors determining their acceptability.

Although the CCCD guidelines' quality and process have been rated highly (**www.gacguidelines.ca**), they suffer from several problems. They are long and detailed. The users' guide to the guidelines[8] offers a more concise, case-based approach that is likely to be easier for physicians to use.

Limitations

There are several limitations to this study. First, it was retrospective and observational. Use of the ICD-9 diagnostic code to identify charts for review could have resulted in undersampling or oversampling, as physicians do not always use these codes accurately. Yet we found very few charts were improperly coded.

Second, a serious limitation of any chart audit is the potential inaccuracy of medical records in documenting what was actually done. Norman et al[22] used standardized patients to compare what physicians actually did with what was recorded. The greatest number of omissions occurred in recording patient education and counseling. Physical examination and laboratory investigations were usually recorded. Stange et al[23] measured delivery of several primary care services and calculated the sensitivity and specificity of chart review compared with direct observation of patient visits by a research nurse. They found the sensitivity of the medical record to be low for measuring counseling on health habits and moderate for physical examinations, laboratory tests, and immunization. The specificity of the medical record was generally high. This suggests that a chart audit might underestimate performance measures associated with counseling, including assessment of caregiver stress, determination of driving safety, or problems with and assessment of ADLs and instrumental ADLs.

Third, although the CCCD guidelines were developed with family physicians in mind, it was clear that the charts and their contents reflected the clinical behaviour of family physicians, medical specialists, and other providers who assessed patients.

Finally, physicians in this audit were practising in urban settings and all were affiliated with university departments of family and community medicine. This setting could limit the generalizability of the results to typical family medicine settings.

Conclusion

Compliance with many recommendations of the CCCD guidelines was fair to good. Levels of assessment or documentation of caregiver coping and caregiver referral for support were low. Levels of assessment or documentation of safety and referral for formal driving evaluation were also low. Physicians overrelied on CT imaging. Future guidelines should address these specific areas.

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Contributors

Dr Pimlott, Dr Seigel, Ms Persaud, Ms Slaughter, Dr Cohen, Ms Cummings, Dr Drummond, Dr Dalziel, Dr Sylvius, *and* **Dr Pringle** *contributed to conception and design of the study.* **Dr Pimlott, Dr Seigel, Ms Persaud, Dr Hollingworth,** *and* **Mr Eliasziw** *contributed to analysis and interpretation of the data.* **Mr Eliasziw** *provided statistical expertise.* **Dr Pimlott** *drafted the article and all of the authors provided critical revision for important intellectual content. All of the authors gave final approval to the article submitted.*

Competing interests

None declared

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