

Quality of Dementia Care in the Community: Identifying Key Quality Assurance Components



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ABSTRACT

Background

Primary care-based memory clinics (PCMCs) have been established in several jurisdictions to improve the care for persons with Alzheimer's disease and related dementias. We sought to identify key quality indicators (QIs), quality improvement mechanisms, and potential barriers and facilitators to the establishment of a quality assurance framework for PCMCs.

Methods

We employed a Delphi approach to obtain consensus from PCMC clinicians and specialist physicians on QIs and quality improvement mechanisms. Thirty-eight candidate QIs and 19 potential quality improvement mechanisms were presented to participants in two rounds of electronic Delphi surveys. Written comments were collected and descriptively analyzed.

Results

The response rate for the first and second rounds were 21.3% (n = 179) and 12.8% (n = 88), respectively. The majority of respondents were physicians. Fourteen QIs remained after the consensus process. Ten quality improvement mechanisms were selected with those characterized by specialist integration, such as case discussions and mentorships, being ranked highly. Written comments revealed three major themes related to potential barriers and facilitators to quality assurance: 1) perceived importance, 2) collaboration and role clarity, and 3) implementation process.

Conclusion

We successfully utilized a consultative process among primary and specialty providers to identify core QIs and quality improvement mechanisms for PCMCs. Identified quality improvement mechanisms highlight desire for multi-modal education. System integration and closer integration between PCMCs and specialists were emphasized as essential for the provision of high-quality dementia care in community settings.

Key words: quality improvement, primary care, chronic disease management, dementia, quality indicators, system integration

INTRODUCTION

The rising prevalence of Alzheimer's disease and related dementias (henceforth referred to as dementia) is emerging as a leading global health system challenge.⁽¹⁾ Effective early diagnosis and management models are required to mitigate its impact on patients, caregivers, and health-care systems.^(2,3) Enhancing primary care capacity is seen as essential towards achieving this goal.⁽⁴⁻¹⁰⁾ However, dementia care predominantly resides with geriatric specialists, who are in short supply in Canada and elsewhere, delaying access to care.⁽¹¹⁾

To enhance the care of persons with dementia, many communities are creating programs to assess persons presenting with cognitive concerns. Many of these have been established as primary care-based memory clinics (PCMCs).^(4-7,9,10,12,13) Initial evaluations suggest that PCMCs can provide timelier assessment, lead to a high degree of satisfaction among referring physicians, patients, and caregivers, and streamline access to specialists.⁽¹¹⁻¹³⁾ In order to retain the fidelity of such programs and consistency with initial training and

practice guidelines, and thus prevent ‘practice drift’ and ensure ongoing high quality of care, quality assurance frameworks are needed.^(9,12,14)

Quality assurance is a process to ensure that care provision meets established standards.⁽¹⁵⁾ Quality Indicators (QIs), based on best practices, define achievable benchmarks and a quality assurance framework facilitates practice improvement through targeted, educational quality improvement mechanisms.^(16,17) To our knowledge, there is no quality assurance framework specific to dementia care in primary care-based settings. This paper describes the results of a consensus approach to identify QIs and quality improvement mechanisms in an Ontario-wide network of interprofessional PCMCs, and identify potential barriers and facilitators to the implementation of a quality assurance framework.^(11,12,18)

METHODS

Protocol and Process

A Delphi technique was deployed to obtain agreement from PCMC clinicians and dementia specialists on preferred QIs and quality improvement mechanisms.⁽¹⁹⁻²³⁾ The Delphi technique is an iterative consensus process, wherein surveys are used to solicit opinions from groups, and responses summarized and redistributed in a subsequent round for consideration. We identified 38 candidate QIs and quality improvement mechanisms for dementia care by reviewing existing clinical guidelines and quality indicator and improvement compendiums developed with standardized methods (Table 1).^(16,24-33,34) Respondents were asked to rate the QIs and quality improvement mechanisms using a continuous integer 9-point scale, with 1 representing the least important and 9 the most important. Written comments were solicited and professional information collected to characterize respondents.

Data Collection

Links to the web-based survey were electronically distributed to all PCMC clinicians ($n = 283$) and Ontario specialists through the Ontario Medical Association sections of geriatric medicine ($n = 123$) and neurologists ($n = 134$), and the Canadian Association of Geriatric Psychiatrists ($n = 305$). Two reminders to complete the survey were sent by e-mail. After each round, QIs and improvement measures in the lower two tertiles of agreement (i.e., with mean ratings less than 7) were excluded, and those remaining were reviewed by the authors guided by respondent comments.⁽³⁵⁾ QIs and quality improvement mechanisms deemed redundant or containing duplicate themes were combined or amended with attention to preserving their intent and conciseness. The authors maintained an audit trail of changes and decision-making points. Data from the preceding round, including number of respondents, rating means, and standard deviations, were included in the subsequent round.

Data Analysis

Descriptive statistics were compiled after each round. Student’s t -test was used to identify significant differences between PCMC clinicians and specialists. SPSS version 23.0 (IBM Corp.) was used, with two-sided p values of $< .05$ as the threshold for statistical significance. Two authors (GH, VB) independently analyzed all written comments using descriptive content analysis⁽³⁶⁾ and incorporated the feedback into the presentation of QIs and quality improvement mechanisms in the second Delphi round.

RESULTS

Two survey rounds were conducted between April and June 2014. In the first Round, 842 surveys were distributed with a response rate of 21.3%. The majority of respondents were physicians, and nurses and other health professionals equally represented the remainder of respondents (Table 2). Respondents had an average of 14.6 ± 10.1 years of clinical practice with older adults. Among PCMC respondents, 31% were from urban centres, 42% rural settings, and 25% from mixed urban/rural populations. In contrast, 73% of specialists worked in urban settings, and 24% served mixed populations. Only 11 neurologists responded to the first survey, and their specialty was not included in Round 2.

In Round 2, 690 surveys were distributed with a response rate of 12.8%. The majority of respondents (60.2%) were physicians. Respondents had an average of 17.42 ± 10.08 years of clinical practice with older adults and practice settings were similar to Round 1. Respondent characteristics are shown in Table 2.

Of the initial 38 candidate QIs, only 14 remained after two Delphi rounds. A third Delphi round was not conducted due to the substantial drop in response rate between Rounds 1 and 2. Table 3 presents the results of the consensus process and Table 4 presents the final list of quality indicators. Of 19 candidate quality improvement mechanisms, 10 were ultimately selected. Quality improvement mechanisms characterized by specialist integration, including case discussions, shared care, observerships, and mentorships, ranked highly (Table 5). Other preferred quality improvement mechanisms included standardized electronic charting forms, self-directed learning activities, and interactive programs. Survey respondents recommended that between 10–30% of patients seen in a PCMC also be reviewed by a specialist.

Respondent Comments

Descriptive content analysis identified three themes related to potential barriers and facilitators to the establishment of a quality assurance framework in PCMCs: 1) its perceived importance, 2) collaboration and role clarity, and 3) the implementation process.⁽³⁶⁾

TABLE 1.
Candidate quality indicators

<i>QI</i>	<i>Short Form</i>	<i>Descriptor</i>
<i>Process Indicators</i>		
1.	Access time	Percentage of patients who are assessed by the PCMC within 3 months of dementia being suspected. ⁽²⁹⁾
2.	Consult note content	Percentage of letters from the PCMC to the referring physician that contain all the following elements: 2.1: diagnosis; ⁽²⁴⁾ 2.2: conclusions concerning the care needs of the patient and caregiver(s); ⁽²⁴⁾ 2.3: medical treatment plan; ⁽²⁴⁾ 2.4: non-medical treatment plan; ⁽²⁴⁾ and 2.5: advice concerning driving safety. ⁽²⁴⁾
3.	Specialist referrals	Percentage of patients referred by the PCMC to a specialist if: 3.1: there is uncertainty about the diagnosis; ⁽²⁹⁾ 3.2: the course of the dementia is rapidly progressive; ⁽²⁹⁾ 3.3: characteristics suggest rare types of dementia, like focal or frontal features or visual hallucinations in early stages of the dementia; ⁽²⁹⁾ 3.4: symptoms or results that suggest disorders that can only be treated by a specialist; ⁽²⁹⁾ 3.5: patient is younger than 65 years; ⁽²⁹⁾ and 3.6: patient's or caregiver's request to confirm the diagnosis. ⁽²⁹⁾
4.	PCMC activity log	Reports describing the activities and characteristics of the PCMC, such as team composition, staff composition, resources, referring physicians, referrals and patient characteristics are produced annually. ⁽²⁴⁾
5.	Client satisfaction	Patient and caregiver(s) satisfaction is measured annually. ⁽²⁴⁾
6.	Referring clinician satisfaction	Referring physician satisfaction is measured annually. ⁽²⁴⁾
<i>Assessment and Reassessment</i>		
7.	Charting completeness	Percentage of clinical diagnostic documentation for dementia in the PCMC that includes the following: 7.1: "history from other sources" (collateral); ⁽²⁹⁾ 7.2: general physical examination; ⁽²⁹⁾ 7.3: neurological examination; ^(25, 29) 7.4: cognitive testing; ⁽²⁹⁾ 7.5: mood screening test; ⁽²⁹⁾ 7.6: assessment of the patient's physical, emotional and social needs; ⁽²⁹⁾ 7.7: assessment of the caregiver's burden and needs; ⁽²⁹⁾ and 7.8: multidisciplinary team discussion of diagnostic outcomes for each patient. ⁽²⁹⁾
8.	Diagnostic supporting data	Percentage of dementia diagnoses that are explicitly supported by the documentation of all of the following criteria: 8.1: acquired and progressive; ⁽²⁹⁾ 8.2: affects two or more cognitive domains; ^(29,30) 8.3: leads to impairment in occupational or social functioning; ^(25,29) 8.4: negative influence on daily functioning; ⁽²⁹⁾ and 8.5: absence of a delirium. ⁽²⁹⁾

TABLE 1.
Continued

<i>QI</i>	<i>Short Form</i>	<i>Descriptor</i>
<i>Assessment and Reassessment</i>		
9.	Annual dementia severity tracking	Percentage of patients with a diagnosis of dementia whose severity of dementia is classified as mild, moderate, or severe at least once within a 12-month period. ⁽³¹⁾
10.	MCI 1-year reassessment	Percentage of patients with Mild Cognitive Impairment (MCI) who are reassessed within 12 months of the initial assessment. ⁽²⁶⁾
11.	Dementia 1-year cognitive review	Percentage of patients with a diagnosis of dementia who undergo an assessment of cognition, and for whom the results are reviewed at least once within a 12-month period. ^(25,28,31)
12.	Dementia 1-year function review	Percentage of patients with a diagnosis of dementia who undergo an assessment of functional status (including activities of daily living and elimination), and for whom the results are reviewed at least once within a 12-month period. ^(25,28,31)
13.	Dementia 1-year behaviour review	Percentage of patients with a diagnosis of dementia who undergo an assessment of neuropsychiatric symptoms, and for whom the results are reviewed at least once within a 12-month period. ^(25,28,31)
<i>Medication Review and Management</i>		
14.	Medication review	Percentage of persons with cognitive impairment for whom a medication review (prescriptions, over the counter or supplements) is undertaken to identify drugs that may be associated with changes in cognitive function. ^(25,28)
15.	Medication review and justification	Percentage of persons with cognitive impairment and who are taking medications commonly associated with mental status changes, and for whom these medications are discontinued or for which continued use is justified due to clearly documented reasons (because removing or decreasing medications might lead to improved cognition). ^(25,28)
16.	Anticholinergic medication review	Percentage of persons with cognitive impairment who are prescribed a medication with anticholinergic effects even though alternatives are available, unless there is an explicit justification for this medication in the medical record. ^(28,30)
17.	Sedative medication review	Percentage of persons with cognitive impairment who are prescribed long-acting sedatives (hypnotics, anxiolytics), unless there is an explicit justification for this medication in the medical record. ^(28,30)
<i>Investigations</i>		
18.	Lab testing	Percentage of persons assessed for cognitive impairment in whom all recommended blood tests are performed, including: Complete Blood Count, creatinine, serum B12, thyroid stimulating hormone, serum electrolytes, serum calcium, and serum fasting glucose. ^(25,26,29)
19.	Neuroimaging	Percentage of patients assessed for cognitive impairment in whom structural cranial imaging is recommended if one or more of the following criteria are present and documented: ⁽²⁶⁾ <ul style="list-style-type: none"> • Age < 65 years; • Rapid (e.g., over 1–2 months) unexplained decline in cognition or function; • Short duration of dementia (< 2 years); • Recent head trauma; • Unexplained neurologic symptoms (e.g., new onset of severe headache or seizures); • History of cancer (especially types that metastasize to the brain); • Use of anticoagulants or history of bleeding disorder; • History of urinary incontinence and gait disorder early in the course of dementia (as may be found in normal pressure hydrocephalus); • Any new localizing sign(s) (e.g., hemiparesis or a Babinski reflex); • Unusual or atypical cognitive symptoms or presentation (e.g., progressive aphasia); and • Gait disturbances.

TABLE 1.
Continued

<i>QI</i>	<i>Short Form</i>	<i>Descriptor</i>
<i>Non-Pharmacological Management</i>		
20.	Diagnosis discussion	Percentage of patients with dementia for whom diagnosis disclosure includes all of the following : 20.1: explicit mentioning of the diagnosis; ⁽²⁴⁾ 20.2: degree of diagnostic certainty (probable or possible); ⁽²⁴⁾ 20.3: information on the prognosis; ⁽²⁴⁾ and 20.4: information about dementia (e.g., about hereditary aspects of dementia, etiology, etc.). ⁽²⁴⁾
21.	Individualized care plan	Percentage of patients with a dementia diagnosis for whom an individualized care plan is formulated. ⁽²⁹⁾
22.	Individualized caregiver support	Percentage of patients with a dementia diagnosis for whose primary caregiver an individualized care plan is formulated. ⁽²⁹⁾
23.	Caregiver education	Percentage of caregivers of patients with dementia who are provided with dementia disease management education and are referred to additional resources for support (e.g., Alzheimer's Society) within a 12-month period. ^(24,25,30,31)
24.	End-of-life planning	Percentage of patients diagnosed with dementia who receive, within 2 years of initial diagnosis or assumption of care, comprehensive counselling regarding ongoing palliation and symptom management and end-of-life decisions. ^(27,30,31)
25.	Advance care plan	Percentage of patients diagnosed with dementia who establish, within 2 years of initial diagnosis or assumption of care, an advanced care plan (e.g., will, enduring power of attorney, personal directive) or surrogate decision-maker in the medical record, or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision-maker or provide advance care plans. ^(28,30,31)
26.	System navigation information	Percentage of caregivers of patients diagnosed with dementia for whom the provision of system navigation information regarding how to access social services for dementia patients and their caregivers is documented. ⁽²⁹⁾
27.	Documented capacity assessment	Percentage of patients with dementia for whom decision-making capacity regarding any care decisions is documented. ⁽²⁷⁾
28.	Overall safety risk assessment	Percentage of patients with dementia for whom safety risk assessments (e.g., driving, financial management, medication management, home safety risks that could arise from cooking or smoking, potentially dangerous behaviours such as wandering) are documented at least once within a 12-month period. ⁽²⁷⁾
29.	Overall safety counselling	Percentage of patients with dementia and/or caregivers who are counselled or referred for counselling regarding safety concerns at least once within a 12-month period. ^(30,31)
30.	Driving counselling	Percentage of patients with dementia and/or caregivers who are counselled regarding the risks of driving and the alternatives at least once within a 12-month period. ^(28,30,31)
31.	Driving assessment	Percentage of patients with dementia in whom driving ability is assessed at least once within a 12-month period. ^(25,30)
32.	Behaviour interventions	Percentage of patients with dementia and one or more neuropsychiatric symptoms who receive or are recommended to receive an intervention for neuropsychiatric symptoms at least once within a 12-month period. ^(28,31)
<i>Pharmacological Management</i>		
33.	Acetylcholine-esterase inhibitor discussion	Percentage of patients diagnosed with mild to moderate Alzheimer's Dementia, mild to moderate vascular dementia, or Lewy body dementia, with whom a discussion with the patient and/or caregiver(s) about risks and benefits of cholinesterase inhibitor treatment is documented. ^(25,28,30)

TABLE 1.
Continued

QI	Short Form	Descriptor
<i>Pharmacological Management</i>		
34	Documented non-pharmacological behavioural intervention	Percentage of patients with dementia and one or more neuropsychiatric symptoms who undergo a trial of prior non-pharmacologic behavioural interventions, and for which the success or failure these measures is documented, before drug treatment targeting these symptoms is initiated. ^(25,30)
35	Antipsychotic risk discussion	Percentage of patients with dementia and neuropsychiatric symptoms, for whom treatment with an antipsychotic is being considered, and for whom a risk–benefit discussion with the patient and/or caregiver(s) is documented. ^(25,28)
<i>Managing Concomitant Conditions</i>		
36.	Nutritional assessment	Percentage of patients diagnosed with dementia and for whom assessment and interventions related to nutritional status are documented. ⁽²⁷⁾
37.	Comorbidity management support	Percentage of caregivers of persons with dementia who receive advice and support on the management of complex comorbidities, such as heart failure or diabetes. ⁽²⁷⁾
38	Stroke prophylaxis	Percentage of persons with dementia and vascular risk factors who are considered treated for stroke prophylaxis, or for whom contraindications to stroke prophylaxis are documented. ^(25,30)

1. Need for and Relevance of Quality Assurance for Dementia Care

Almost all respondents mentioned the need to maintain high-quality care through ongoing, targeted training on pertinent clinical knowledge and consistency of approach among PCMC teams. Most recognized a formal quality assurance framework and individual QIs as essential.

“Great indicators and very necessary” [PCMC clinician, Round 1].

“Our challenge is to maintain evidence based salience, which ultimately facilitates improved quality of life for persons with dementia and their family” [PCMC clinician, Delphi Round 2].

“All are relevant quality indicators for a PCMC” [Specialist, Round 2].

However, a few respondents were unsure why a quality assurance framework was needed at all. Some assumed that formal training should be sufficient to ensure quality. Others seemed unfamiliar with the purpose of quality assurance and construed the idea of tracking QIs as supplemental work.

“Is the intent of the questions to assess what we are doing now or [what] we think should be the standard?” [PCMC clinician, Round 1].

“This is the Canadian Consensus Guideline that *every doc should know*” [Specialist, Round 1; emphasis added by authors].

2. Collaboration and Role Clarity

A second theme pertained to the operationalization and implementation of the quality assurance framework within the context of PCMCs, and identified a lack of clearly delineated responsibilities among referring clinicians, PCMCs, and specialists. Respondents perceived this as problematic because absence of clarity impedes the capture of clinical documentation relevant to QI measurement.

“Not clear on the team role with caregiver and patient care plan. Information is sent back to referral physician with recommendations for caregiver and patient mostly related to change in medication or treatment, lifestyle modification and support resources” [PCMC clinician, Round 2].

This lack of clarity was considered most problematic with regard to patient follow-up.

“Patients with dementia with great plans should not need constant surveillance and follow up BUT... This is not my experience... they appear to often benefit from a watchdog team to ensure their decisions are being carried out.” [Specialist, Round 1].

TABLE 2.
Respondent characteristics for both Delphi rounds

<i>Disciplines</i>	<i>Round 1 (N = 179): % (n)</i>		<i>Round 2 (N = 88): % (n)</i>	
Physicians	63.1% (112)		60.2% (53)	
• PCMC	25.0% (28)		35.8% (19)	
• Geriatrician	34.8% (39)		34.0% (18)	
• Geriatric Psychiatrist	30.4% (34)		30.2% (16)	
• Neurologist	9.5% (11)		Not applicable ^a	
Nursing (RN, R/LPN, NP)	16.2% (29)		15.9% (14)	
Allied Health Professionals	16.2% (29)		20.5% (18)	
Other	5.0% (9)		3.4% (3)	
<i>Practice settings (%)</i>	<i>PCMC Clinicians (N = 95)</i>	<i>Specialists (N = 84)</i>	<i>PCMC Clinicians (N = 54)</i>	<i>Specialists (N = 34)</i>
Urban	30.5 (29)	72.6 (61)	24.1 (13)	44.3 (26)
Rural/remote	42.1 (40)	2.4 (2)	40.7 (22)	2.9 (1)
Mixed urban/rural	25.3 (24)	23.8 (20)	35.2 (19)	20.6 (7)
<i>Clinical practice experience</i>	<i>PCMC Clinicians (N = 78)</i>	<i>Specialists (N = 77)</i>	<i>PCMC Clinicians (N = 50)</i>	<i>Specialists (N = 31)</i>
Mean (SD), years	13.09 (10.5)	16.09 (9.4)	15.32 (9.5)	20.81 (10.2)

^aRound 2 surveys were not distributed to neurologists.

RN = Registered Nurse; RPN = Registered Practical Nurse; LPN = Licensed Practical Nurse; NP = Nurse Practitioner; Other = Professionals from the Alzheimer's Society and other community support services, physician assistants, and administrators. Allied Health Professionals included social workers, occupational therapists, physiotherapists, and pharmacists.

Similar concerns were raised regarding the management of comorbidities.

"... [My] assumption is that management of comorbidities is the primary care physician's domain. Recommendations are made for lifestyle changes, however [congestive heart failure] and diabetes management are only commented on, suggestions are made to the referring physician" [PCMC clinician, Round 2].

It was not clear which health care provider should conduct a physical examination, leading to gaps in assessment.

"Referring Family Physicians are expected to have completed a complete physical including appropriate neuro exam prior to referral" [PCMC clinician, Round 1].

"My biggest concern is that the PCMC team assumes that a proper physical and neurologic exam has been done by the referring source" [Specialist, Round 1].

3. Process of QA Framework Implementation in PCMCs

Respondents provided several comments on potential barriers to the implementation process of a quality assurance framework in PCMCs. One of the main obstacles was the perceived burden of documentation required to implement QIs.

"[It will take a lot of work to do the] searching and documenting as a group of patients needs a process to set up how to search, then doing the search" [PCMC clinician, Round 2].

Integrating QIs into existing electronic medical records was touted as a solution, though potentially a resource-intensive one.

"Searches are limited by consistency of nomenclature in the chart. Making up stamps to collect this information is doable but takes time for someone to make the [standardized template] and then to test it" [PCMC clinician, Round 2].

TABLE 3.
Summary of Quality Indicator selection process

<i>QI</i>	<i>Short Form</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Respondents' Comments</i>
<i>Process indicators</i>					
1.	Access time	6.86 (1.95)	n/a	No	Excluded after Round 1 due to rating below 7.
2.	Consult note content			No	Excluded after review.
2.1		7.75 (1.66)	8.01 (1.08)		Survey respondent comments raised concerns about how to measure this, given the perceived role confusion between referring physicians and PCMC clinicians: <i>'There may be some confusion between the treatment plan and the treatment recommendations left up to the referring physician to manage [PCMC clinician, Round 1].'</i>
2.2		8.11 (1.20)	8.09 (1.07)		
2.3		8.03 (1.28)	8.12 (1.10)		
2.4		7.91 (1.38)	7.68 (1.43)		
2.5		8.15 (1.41)	7.55 (1.78)		
3.	Specialist referrals			Yes	Final Quality Indicator (FQI) 1
3.1		7.56 (1.68)	7.19 (1.71)		Sub-item 3.6 excluded after Round 1 due to low rating. Sub-item 3.5 scored below 7 after Round 2 but was retained, as this PCMC model explicitly stipulates that patients younger than 65 with suspected dementia will be referred to a specialist. After review, sub-items 3.1 to 3.5 combined into a single FQI.
3.2		7.81 (1.68)	7.11 (1.76)		
3.3		7.63 (1.81)	7.30 (1.69)		
3.4		7.62 (2.00)	7.06 (1.94)		
3.5		7.26 (2.03)	6.84 (2.08)		
3.6		6.82 (2.00)	n/a		
4.	PCMC activity log	6.40 (1.98)	n/a	No	Excluded after Round 1 due to rating below 7.
5.	Client satisfaction	6.98 (1.73)	n/a	No	Excluded after Round 1 due to rating below 7.
6.	Referring clinician satisfaction	6.94 (1.62)	n/a	No	Excluded after Round 1 due to rating below 7.
<i>Assessment and Reassessment</i>					
7.	Charting completeness			Yes	FQI 2 (modified after review)
7.1		7.98 (1.30)	8.09 (1.27)		Sub-item 7.2 (general physical examination) was excluded after Round 1 due to rating below 7. Sub-item 7.3 (screening neurological examination) was excluded after Round 2 due to rating below 7. However, there was a statistically significant difference between ratings by PCMC clinicians (6.35 (1.91)) and specialists (7.28 (1.53)); the latter favouring sub-item 7.3. Sub-item 7.6 had an overall rating over 6.99, but the review excluded the sub-item (patient needs in multiple domains) because respondents considered it potentially too variable to permit a sufficiently specific definition to allow for accurate measurement. One respondent commented: <i>"Referral, further testing and reassessment are important but should also be based on patient/caregiver complaints and needs" [Specialist, Round 1].</i> Sub-item 7.8 had an overall rating over 6.99, but the review (documentation of multidisciplinary discussion) excluded the sub-item because it is a required process in the PCMC model of care, variability exists in the multidisciplinary composition of individual teams, and documentation of whether or not a discussion occurred does not reflect the quality and content of the discussion and can therefore not be easily assessed as a QI: <i>"At our Memory Clinic, each patient cannot be followed up in our Memory Clinic annually because of limited resources" [PCMC clinician, Round 2].</i> The remaining sub-items (7.1, 7.4, 7.5, and 7.7) were combined into a single QI (FQI 2) of readily measurable clinical diagnostic documentation.
7.2		6.79 (1.94)	n/a		
7.3		7.16 (1.89)	6.71 (1.82)		
7.4		8.50 (1.06)	8.31 (1.12)		
7.5		8.17 (1.07)	7.72 (1.42)		
7.6		8.22 (1.00)	7.96 (1.26)		
7.7		8.23 (1.06)	8.10 (1.30)		
7.8		7.72 (1.44)	7.27 (1.78)		

TABLE 3.
Continued

<i>QI</i>	<i>Short Form</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Respondents' Comments</i>
<i>Assessment and Reassessment</i>					
8.	Diagnostic supporting data		7.69 (1.37)	Yes	FQI 3 (modified after review)
8.1		7.41 (1.73)			Sub-items 8.1 to 8.5 were combined into one QI (FQI 3) after Round 1 due to general agreement for inclusion (mean ranking = 7.72, range 7.41–7.92, no significant differences between groups). Furthermore, all 5 sub-items reflect important elements of the dementia diagnosis and are thus conceptually related.
8.2		7.49 (1.68)			
8.3		7.90 (1.46)			
8.4		7.92 (1.37)			
8.5		7.87 (1.43)			
9.	Annual dementia severity tracking	7.10 (1.52)	n/a	No	Excluded after Round 1 because this QI was deemed too similar to, though less easily defined, than an assessment of functional status as an indicator of dementia severity of dementia (QI 12). Survey respondents commented: “ <i>Not sure how the PCMC could accurately determine severity of dementia as mild, moderate or severe</i> ” [Specialist, Round 2]; “ <i>Confusion re: mild, moderate, severe dementia....so we don't use these terms consistently...or really much at all</i> ” [PCMC clinician, Round 2].
10.	MCI 1-year reassessment	7.37 (1.62)	7.26 (1.66)	Yes	FQI 4
11.	Dementia 1-year cognitive review	7.40 (1.40)	7.42 (1.48)	Yes	FQI 5 (integrated with QIs 12, 28 and 32 after review as conceptually similar).
12.	Dementia 1-year function review	7.58 (1.39)	7.56 (1.53)	Yes	FQI 5 (integrated with QIs 11, 28, and 32 after review).
13.	Dementia 1-year behaviour review	7.39 (1.57)	6.86 (1.84)	No	Excluded after Round 2 due to rating below 7.
<i>Medication Review and Management</i>					
14.	Medication review	8.47 (1.01)	8.27 (1.30)	Yes	FQI 6: integrated after review with QIs 15 to 17 due to substantial content overlap. Survey respondents commented: “ <i>I think justifying every medication that could have cognitive effects and documenting this with every patient would be too detailed,</i> ” and “ <i>Of utmost importance is the identification of the medication (prescribed and OTC).</i> ” [Specialist, Round 2].
15.	Medication review and justification	8.09 (1.42)	7.82 (1.35)	Yes	QIs 15 to 17 were combined into one QI after Round 1 due to substantial overlap in content. The remaining QI was integrated with QI 14 into FQI 6 after review.
16.	Anticholinergic medication review	7.53 (2.01)			
17.	Sedative medication review	7.51 (1.98)			
<i>Investigations</i>					
18.	Lab testing	8.02 (1.35)	7.79 (1.34)	Yes	FQI 7
19.	Neuroimaging	8.13 (1.17)	7.90 (1.33)	Yes	FQI 8

A second issue identified in relation to the implementation of the quality assurance framework is the need to establish benchmarks to properly interpret QI scores. Respondents suggested that specialist involvement with PCMCs could help define these benchmarks. However, access to specialists within a PCMC was often seen as insufficient.

“I think one of the most important quality indicators is a comparison of the PCMC performance versus

the specialist, done on both patients referred to the specialist by the PCMC, and unselected patients seen in the clinic that would not have been referred to the specialist” [Specialist, Round 1].

Access to other health care professionals, within PCMCs and in the community, was identified as important for quality care, though access was not perceived as uniform.

TABLE 3.
Continued

<i>QI</i>	<i>Short Form</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Respondents' Comments</i>
<i>Non-Pharmacological Management</i>					
20.	Diagnosis discussion			No	QI and all sub-items were excluded after review. While all sub-items ranked above 6.99, several survey respondents expressed concerns that the amount of information to be discussed regarding diagnosis and implications can only be delivered over several appointments, thus making accurate and meaningful measurement of this QI difficult: <i>"Patients and their family are often overwhelmed at the time of feedback...and would not be able to absorb all this information" [PCMC clinician, Round 1]; "The conveyance of information could take place over several weeks or months as the amount of information mentioned above (and important to convey) would be likely to be overwhelming to a patient and family with a new dx of dementia. So I think it is important that all above info be conveyed, but possibly with proviso that it be within 1–3 months of initial diagnosis" [Specialist, Round 2].</i>
20.1		7.93 (1.35)	7.85 (1.18)		
20.2		7.45 (1.45)	7.41 (1.30)		
20.3		7.61 (1.31)	7.70 (1.19)		
20.4		7.24 (1.59)	7.37 (1.36)		
21.	Individualizing care plan	7.82 (1.40)	n/a	No	Excluded after Round 1 review. This QI was considered too vague and potentially too variable to permit a sufficiently specific definition to allow for accurate measurement. Survey respondents commented: <i>"There may be challenges in interpreting documentation for some of these factors (i.e. may not be explicit)" [PCMC clinician, Round 1].</i>
22.	Individualized caregiver support	7.66 (1.46)	n/a	No	Excluded after Round 1 review. QI was considered too vague and potentially variable to permit a sufficiently specific definition to allow for accurate measurement. A PCMC clinician stated: <i>"Care plans for caregivers is tricky because they are not necessarily your patient and may not share the same family physician as the index patient" [PCMC clinician, Round 1].</i>
23.	Caregiver education	8.13 (1.28)	n/a	No	Excluded after Round 1 review. Referral to external resources for support, particularly the Alzheimer's Society, is an intrinsic aspect of CFFM PCMC clinic processes and staffing. Furthermore, documentation of whether the referral is made does not ensure that the referral took place and whether or what type of support was provided. Survey respondents commented: <i>"This is difficult to answer in some ways because it's asking about the clinic alone. A lot of this work is done in collaboration with community partners" [PCMC clinician, Round 1].</i>
24	End-of-life planning	7.19 (1.81)	6.52 (1.89)	No	Excluded after Round 2 due to rating below 7.
25.	Advance care plan	7.62 (1.57)	7.28 (1.71)	Yes	FQI 9
26.	System navigation information	7.60 (1.62)	7.14 (1.59)	No	Excluded after review. System navigation services might be provided by resources external to PCMCs and therefore are not easily measurable or reflective of the care at the PCMC program <i>per se</i> . See survey respondent comments to QI 23.
27	Documented capacity assessment	7.42 (1.77)	7.10 (1.69)	No	Excluded after review. Capacity for decision-making is an intrinsic component of advanced care planning, addressed by FQI 9. Furthermore, in practice, this process often involves shared care with the specialist, to which referrals are addressed by care processes inherent in the PCMC model. Survey respondents raised concerns about measurability, as capacity changes over time: <i>"Regarding capacity to make decisions - since capacity is decision specific - you may not have the opportunity to assess this within a 12 month period if the need for a specific decision does not arise" [Specialist, Round 2].</i>

TABLE 3.
Continued

<i>QI</i>	<i>Short Form</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Respondents' Comments</i>
<i>Non-Pharmacological Management</i>					
28.	Overall safety risk assessment	8.06 (1.38)	8.06 (1.21)	Yes	FQI 5 but integrated with QIs 11, 12, and 32 after review. This QI was then integrated into a single QI relating to 12-month reassessment.
29.	Overall safety counselling	7.45 (1.76)	7.28 (1.51)	No	Excluded after review due to significant overlap with QI 28.
30.	Driving counselling	7.94 (1.52)	8.10 (1.08)	Yes	Accepted with modification after review (FQI 10). This QI was reworded after review to address that this only applies to patients that are still able to drive.
31.	Driving assessment	7.89 (1.60)	7.61 (1.53)	Yes	FQI 11 was reworded after review to address that this only applies to patients that are still able to drive.
32.	Behaviour intervention	7.46(1.76)	7.22(1.53)	Yes	FQI 5 (integrated with QIs 11, 12, and 28 after review). This QI was then integrated into a single QI relating to 12-month reassessment.
<i>Pharmacological Management</i>					
33.	Acetylcholine-esterase inhibitor discussion	7.81 (1.46)	7.96 (1.24)	Yes	FQI 12
34.	Documented non-pharmacological behavioural intervention	7.41 (1.72)	7.24 (1.76)	Yes	FQI 13 (combined with QI 35 after review because of substantial conceptual overlap. Statistically significant difference with specialists favouring this QI more than PCMC clinicians (7.81 (1.26) vs. 6.85 (1.96), $p < .01$).
35.	Antipsychotic risk discussion	7.72 (1.75)	7.57 (1.59)	Yes	FQI 13 (combined after investigator review with QI 34 because of substantial conceptual overlap)
<i>Managing concomitant conditions</i>					
36.	Nutritional assessment	6.88 (1.73)	n/a	No	Rating below 7 after Round 1.
37.	Comorbidity management support	7.00 (1.75)	7.13 (1.45)	No	Excluded after review because of differences between PCMC staff and specialist ratings (6.96 (1.43) and 7.13 (1.45)). Several survey respondent comments raised concerns about how to measure this given role confusion between referring physicians and PCMC. Survey respondents commented: "The prophylaxis and chronic disease care is done by the family doctor." [PCMC clinician, Round 1]; "Advice and support on management of complex comorbidities should certainly be recommended to the patient's family doctor, but not necessarily within the purview of the PCMC itself." [Specialist, Round 1]; "Managing concomitant conditions is important but not always feasible given the complexity of dementia assessment" [Specialist, Round 2].
38.	Stroke prophylaxis	7.15 (1.69)	7.41 (1.57)	Yes	FQI 14

"Having a pharmacist on our team is a great asset... The local [pharmacists] volunteer their time to assist us at our once monthly day long clinics" [PCMC clinician, Round 2].

"The [Social Work] and [Occupational Therapy] members of the team do an excellent job...the [Alzheimer's Society] representative has been excellent as well when given an opportunity" [PCMC clinician, Round 2].

An important finding is the relative lack of importance ascribed to end-of-life planning. While respondents agreed on its importance, many expressed that such planning discussions were not appropriate for patients with less advanced disease.

"Palliation and end of life discussion is usually not appropriate at time of our memory clinic initial or follow-up assessment since our patients are not that advanced. Family physician team will do this in following up patient" [PCMC clinician, Round 1].

TABLE 4.
Final Quality Indicators (FQIs) and operational definitions

<i>Numerator</i>	<i>Denominator</i>
<i>Process Indicators</i>	
<p>FQI 1: Patients referred by the PCMC to a specialist if one or more of the following is documented:</p> <ol style="list-style-type: none"> 1. Course of the dementia is rapidly progressive; 2. Characteristics suggest rare types of dementia, such as focal or frontal features or visual hallucinations in early stages of the dementia; 3. Persistent patient or caregiver complaints of problematic symptoms, or unexplained investigation results; 4. Uncertainty about the diagnosis; and 5. Patient is younger than 65 years. 	All patients seen in the PCMC with documentation of one or more of these 5 indicators.
<i>Assessment and Reassessment Indicators</i>	
<p>FQI 2: Proportion of patients seen in PCMC with clinical diagnostic documentation for dementia, whereby the documentation includes <u>ALL</u> of the following:</p> <ol style="list-style-type: none"> 1. "History from other sources" (collateral); 2. Cognitive testing; 3. Assessment of caregiver's burden and needs; and 4. Mood screening test. 	All patients seen in the PCMC.
<p>FQI 3: Proportion of patients seen in PCMC that have a documented diagnosis of dementia that is explicitly supported by documentation of <u>ALL</u> of the following criteria:</p> <ol style="list-style-type: none"> 1. Acquired and a decline from previous function; 2. Affects two or more cognitive domains; 3. Leads to impairment in occupational or social functioning; 4. Negative influence on daily functioning; and 5. Absence of a delirium. 	All patients seen in the PCMC and who are diagnosed with dementia.
<p>FQI 4: Proportion of patients seen in the PCMC who have a documented diagnosis of Mild Cognitive Impairment (MCI) and who are reassessed within 12 months of the initial assessment.</p>	All patients seen in the PCMC with a documented diagnosis of MCI.
<p>FQI 5: Proportion of patients seen in the PCMC who have a documented diagnosis of dementia and who are reviewed at least once within a 12-month period to undergo an assessment for:</p> <ol style="list-style-type: none"> 1. Cognition; 2. Function; 3. Behavioural and neuropsychiatric symptoms; and 4. Safety concerns (driving, financial management, medication management, home and environmental risks, wandering). 	All patients seen in the PCMC and who are diagnosed with dementia.
<i>Medication Review and Management Indicators</i>	
<p>FQI 6: Proportion of patients seen in the PCMC who have a documented diagnosis of dementia or MCI, who are taking medications commonly associated with mental status changes, and for whom these medications are either:</p> <ol style="list-style-type: none"> 1. Discontinued, or 2. Continued but with clearly documented justification outlining why their expected benefits outweigh their potential negative impact on cognition. 	All patients seen in the PCMC diagnosed with dementia or MCI, and who are taking medications associated with mental status changes.
<i>Investigations Indicators</i>	
<p>FQI 7: Proportion of patients seen in the PCMC that are assessed for cognitive impairment and in whom all recommended blood tests are performed, including: Complete blood count, creatinine, serum B12, thyroid stimulating hormone, serum electrolytes, serum calcium, and serum fasting glucose.</p>	All patients seen in the PCMC.

Lastly, many respondents expressed a preference for quality improvement mechanisms and learning opportunities characterized by active engagement. They also identified specialists as agents to promote care quality, particularly in the context of a shared care approach.

"This [case review] could be done at the same time, as the specialist mentoring the clinic is in a clinic day with the team" [PCMC clinician, Round 1].

TABLE 4.
Continued

<i>Numerator</i>	<i>Denominator</i>
<i>Process Indicators</i>	
<p>FQI 8: Proportion of patients seen in the PCMC that are assessed for CI in whom structural cranial imaging is recommended if <u>one or more</u> of the following criteria are present and documented:</p> <ol style="list-style-type: none"> 1. Age < 60 years; 2. Rapid (e.g., over 1–2 months) unexplained decline in cognition or function; 3. Short duration of dementia (< 2 years); 4. Recent head trauma; 5. Unexplained neurologic symptoms (e.g., new onset of severe headache or seizures); 6. History of cancer (especially types that metastasize to the brain); 7. Use of anticoagulants or history of bleeding disorder; 8. History of urinary incontinence and gait disorder early in the course of dementia (as may be found in normal pressure hydrocephalus); 9. Any new localizing sign (e.g., hemiparesis or a Babinski reflex); 10. Unusual or atypical cognitive symptoms or presentation (e.g., progressive aphasia); and/or 11. Gait disturbances. 	All patients seen in the PCMC and in whom one or more of these features is documented.
<i>Non-Pharmacological Management Indicators</i>	
<p>FQI 9: Proportion of patients seen in the PCMC with a documented diagnosis of dementia for whom, within 2 years of initial dementia diagnosis, an advance care plan (e.g., will, enduring power of attorney, personal directive) is established and a surrogate decision-maker identified in the medical record, unless it is documented in the medical record that the patient did not wish to, or was not able to, name a surrogate decision-maker or provide advance care plans.</p>	All patients seen in the PCMC and who are diagnosed with dementia.
<p>FQI 10: Proportion of patients seen in PCMC, who have a driver's license and/or are driving with a documented diagnosis of dementia, and/or their caregivers, and who received counselling regarding the risks of driving and the alternatives at least once within a 12-month period.</p>	All patients seen in the PCMC, diagnosed with dementia, and who have a valid driver's license and/or are driving.
<p>FQI 11: Proportion of patients with dementia who have a driver's license and/or are driving in whom driving ability is assessed at least once within a 12-month period.</p>	All patients seen in the PCMC, diagnosed with dementia, and who have a valid driver's license and/or are driving.
<i>Pharmacological Management Indicators</i>	
<p>FQI 12: Proportion of patients seen in the PCMC with a documented diagnosis of mild to moderate Alzheimer's Dementia, mild to moderate vascular dementia, or Lewy body dementia, with whom a discussion with the patient and/or caregiver about the risks and benefits of cholinesterase inhibitor treatment is documented.</p>	All caregivers and/or patients seen in the PCMC with a documented diagnosis of mild to moderate Alzheimer's Dementia, mild to moderate vascular dementia, or Lewy body dementia.
<p>FQI 13: Proportion of patients with dementia and neuropsychiatric symptoms, for whom an antipsychotic is prescribed, and for whom a discussion considering non-pharmacological options and potential benefits and harms of these medications, had taken place and has been documented in the patient's record.</p>	Patients seen in the PCMC and who have been prescribed an antipsychotic medication.
<i>Managing Concomitant Conditions Indicators</i>	
<p>FQI 14: Proportion of patients as seen in the PCMC with a documented diagnosis of dementia and vascular risk factors who are considered for stroke prophylaxis.</p>	All patients referred to the PCMC, who have vascular risk factors, and who have no documented contraindications for stroke prophylaxis. The management of patients with severe dementia (as per Clinical Dementia Rating Scale) should be considered on an individual basis and fall beyond the scope of this QI.

TABLE 5.
Ranking of Quality Improvement mechanisms

<i>Mechanism</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Comments From Respondents</i>
Case discussions	7.63 (1.48)	7.72 (1.30)	Yes	<p>Specialist comments:</p> <ul style="list-style-type: none"> • “I think case reviews with a specialist are a great way to train/upgrade/empower a PCMC team to perform better/more independently over time.” • “...to be honest, I think all PCMCs should review all cases with a specialist for at least the first year or two, with full consult/review [...], depending on PCMC team confidence, on a case by case basis after that.” • “Case reviews would be useful but the expectation is impractical given the scarcity of geriatric specialist resources.”
Mixed didactic/interactive programs: Regular conferences for all PCMCs (Booster day sessions)	7.5 (1.64)	7.64 (1.24)	Yes	<p>PCMC clinician comments:</p> <ul style="list-style-type: none"> • “Booster Days are great...and the opportunity to send new team members to MC training is vital.” • “Booster days are extremely useful and recharging.”
Standardized clinical charting forms	7.39 (1.79)	7.51 (1.27)	Yes	
Clinical observership/mentorship/shared consults	7.73 (1.43)	7.42 (1.34)	Yes	<p>PCMC clinician comments:</p> <ul style="list-style-type: none"> • “This could be done at the same time as the specialist mentoring the clinic is in a clinic day with the team.” • “In a perfect world it would be great to have all assessed by specialist.” <p>Specialist comments:</p> <ul style="list-style-type: none"> • “I think the key parameter here will be a peer assessment by a third party.”
Self-directed learning	7.29 (1.73)	7.33 (1.38)	Yes	
Clinical reasoning models/algorithms	7.28 (1.77)	7.29 (1.44)	Yes	
On-site case reviews with PCMC team	7.26 (1.78)	7.29 (1.47)	Yes	
Interactive programs: Communities of Practice, networking, shared experiences, problem-solving	7.15 (1.71)	7.15 (1.60)	Yes	<p>PCMC clinician comments: “Very interesting to share information and discuss about difficult cases but not realistic to obtain a network between the clinics. Could be possible though within small groups.”</p>
Regular chart audits and feedback	7.02 (1.65)	6.96 (1.59)	Yes	<p>While the score on the second Delphi round was less than 7.00, audit and feedback is intrinsic to QA, and therefore it was retained.</p> <p>PCMC clinician comment: “Always open to improving our care at memory clinic by having feedback from experts.”</p>
E-learning modules	7.02 (1.78)	n/a	Yes	<p>This mechanism was unintentionally dropped from the second Delphi survey. After discussion, a decision was made to retain it given the likelihood that ratings would not have changed substantially, and taking into consideration the comment below.</p> <p>PCMC clinician comment: “E-learning, DVD, Journal club and webinars, written papers etc... would be useful but it is being able to fit those into our busy schedules and other responsibilities.”</p>
Electronic reminders/cues	7.09 (1.82)	6.73 (1.82)	No	Rating below 7.00
Distribution of written material	6.72 (1.94)	n/a	No	Rating below 7.00

TABLE 5.
Continued

<i>Mechanism</i>	<i>Round 1 Mean (SD)</i>	<i>Round 2 Mean (SD)</i>	<i>Accepted?</i>	<i>Review Details and Comments From Respondents</i>
Webinars	6.71 (1.66)	n/a	No	Rating below 7.00
Web-based/DVD videos	6.62 (1.96)	n/a	No	Rating below 7.00
Regular Mandated Patient Consultations	6.52 (1.95)	n/a	No	Rating below 7.00
Pocket Cards	6.32 (2.12)	n/a	No	Rating below 7.00
Mobile Apps	6.32 (2.15)	n/a	No	Rating below 7.00
Didactic programs: Lectures/presentations	6.30 (1.95)	n/a	No	Rating below 7.00
Journal clubs	6.25 (1.97)	n/a	No	Rating below 7.00

Overall, respondents recognized the need for a quality assurance framework for dementia care. Barriers to the implementation of this framework included role confusion among stakeholders and limited resources. Integrated electronic data collection was considered a facilitator for quality assurance.

DISCUSSION

This study used a consultative process among primary and specialty providers to identify a core group of QIs and preferred quality improvement mechanisms for dementia care. Quality assurance can be an effective method to ensure fidelity to best practices and maintain a high standard of care quality.⁽³⁷⁻⁴¹⁾ Selected QIs address care processes, assessment and reassessment, medication review and management, investigations, non-pharmacological management, pharmacological management, and managing concomitant conditions.⁽⁴²⁾ Selected quality improvement mechanisms emphasize a desire for multimodal education and closer collaboration with specialists. Assessing care quality and publically reporting the findings are increasingly commonplace. However, quality assurance still mainly focuses on specific care sectors or episodes, rather than on overall care for conditions that require coordination and collaboration across multiple sectors.⁽⁴³⁾ In that context, study participants identified important hurdles to its implementation.

Critical considerations include educating clinicians about the role of quality assurance, improving role clarity among providers involved in dementia care, expanding access to allied health professionals, and creating standardized electronic medical record templates to simplify QI documentation. Quality assurance must not create additional burden on clinicians often working with limited resources and time, a burden that could also impact the quality of the clinician-patient interaction. Greater integration of specialists within PCMCs was acknowledged as important for care quality. Respondents proposed that 10–30% of patients seen

in PCMCs be reviewed with a specialist, preferably in a shared care approach. Closer integration of urban specialists with rural PCMCs represents a tremendous opportunity to extend quality dementia care, particularly to rural patients. However, integration of specialists within PCMCs remains suboptimal. To optimize specialist integration, it will be necessary to identify barriers (e.g., allocation of funding) and facilitators (e.g., resources for coordination, electronic medical records, telemedicine). Another important finding was the relatively low rankings of QIs related to end-of-life planning with dementia patients. In addition to potential discomfort among clinicians to address such issues, this finding may also stem from the understandable desire to maintain hope and engagement early in the course of the illness, though undue delays may leave patients and caregivers less able to meaningfully participate in such discussions.

The most important identified barrier to the implementation of the quality assurance framework is the need for greater clarity on responsibilities of referring family physicians, PCMC clinicians, and specialists, particularly with respect to follow-up, physical examination, and care of complex comorbidities. Quality assurance often targets relatively simple conditions, such as hypertension, or restricts its scope to specific aspects, processes or locations of care.⁽³⁸⁻⁴¹⁾ In contrast, dementia, like all major chronic conditions, follows a course of progressive decline punctuated by increasingly frequent health complications (related to dementia itself, as well as to exacerbations of concurrent comorbidities), multiple care transitions, progressive caregiver stress and health service utilization, and ultimately death. Optimal dementia care thus requires a systems approach of integration and coordination.^(44,45) Addressing greater role clarity among all dementia stakeholders, a task that with proper resources could be coordinated from within PCMCs, requires immediate attention, in order to ensure a stable clinical infrastructure that is able to safely and effectively address the needs of these patients, wherever they may be and whenever they arise.^(46,47) Until

such integration is achieved, optimal quality dementia care will remain difficult to attain.

Limitations of the Study

The results of this study should be understood in light of several limitations. First, only two Delphi rounds were conducted because the response rate fell markedly after the first. However, the response rate remained above what is considered appropriate for Delphi surveys, and ratings of individual QIs, except those related to physical examination, remained stable between rounds.^(48,49) A second limitation is that the survey was solely distributed within the previously described network of PCMCs,⁽¹¹⁻¹³⁾ though this model is widely implemented across Ontario. As the QIs were selected by both primary and specialist providers, they are likely applicable to other dementia care settings. Third, participation of neurologists in the first round was low and their response was not solicited in the second round. The relatively lower participation of neurologists in this work, compared to geriatricians and geriatric psychiatrists, is notable and requires further investigation. Fourth, allied health providers were under-represented and, given their importance in dementia care, additional work is required to further understand and develop their role in an integrated system of dementia care. Fifth, patient and caregivers were not surveyed regarding what they consider to be important QIs. Finally, candidate QIs and quality improvement mechanisms were not identified through a systematic literature review, but the use of published guidelines and compendiums likely identified the most important elements of quality dementia care, which would thus have remained highly ranked.

CONCLUSIONS

While this study has identified QIs and quality improvement mechanisms to assess care quality for dementia, findings underscore the importance of system integration for the provision of quality dementia care, with specifically defined and mutually understood roles among stakeholders and, where necessary, the reallocation of existing resources to support this approach to care.⁽⁵⁰⁾ Understanding and overcoming system barriers to dementia care integration is an urgent priority. An approach whereby clear roles are negotiated among dementia stakeholders can provide sufficient flexibility to meet regional needs (especially in rural areas where access to specialists is more limited), foster more effective collaboration and accountability, and thus facilitate the delivery and measurement of care quality for dementia. Within that context, proper field-testing, validation, and evaluation of selected QIs and quality improvement mechanisms can then be conducted. This work has significant implications on the organization of care for aging patients with complex conditions. Primary and specialist providers share the responsibility of providing and supporting integrated dementia quality care. As such,

the care of persons with cognitive impairment would be enhanced by the development of a practical and realistically feasible quality assurance framework, under whose umbrella both PCMC and specialist services are integrated, and which ensures high fidelity to intended design and best practices, and thus maintains a high level of care quality.⁽⁵¹⁾

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CONFLICT OF INTEREST DISCLOSURES

VB receives salary support from CIHR, Conestoga College, and Schlegel Villages. DS served on an advisory board for Eli-Lilly in 2013. No other conflicts of interest to declare.

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