



## Validation of the Family Physicians' Perception of Dementia Care Questionnaire: A Pilot Study

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### Abstract

**Background:** Aging is a major risk factor for dementia and evidence shows that community-dwelling elderly are underdiagnosed and undertreated. Family physicians (FP), as gatekeepers, play a crucial role in the diagnosis and management of dementia; hence an understanding of their perspective during this process is important. Currently, few studies have examined the Canadian FPs perspective towards dementia diagnosis using a validated questionnaire. Thus, a questionnaire to appraise FPs practices in the diagnosis and management of dementia was developed and validated.

**Methods:** A self-administered questionnaire regarding dementia-related attitudes and practices of FPs was developed using items derived from published studies. Psychometric properties of the questionnaire were appraised.

**Results:** A questionnaire of 23 items using a 5-point Likert-scale format was developed. Eighty New Brunswick FPs provided responses to the questionnaire. Five categories pertaining to the diagnosis and management of dementia (knowledge, available resources, screening practices, skills and referral to specialists) and two categories (facilitating and unfavorable attitudes) regarding attitudes towards dementia were yielded from the analyses.

**Conclusions:** The present questionnaire can serve as a valid toolkit to assess FPs and other primary care provider's perceptions on the diagnosis and management of dementia. This consequently helps enhancing dementia care, and policymaking.

### Keywords

Family physician, Attitudes, Dementia, Diagnosis, Survey

### Introduction

Alzheimer's disease and other dementias currently affect approximately 500,000 Canadians and this number could increase by several-fold in the coming decades [1]. Current evidence shows

that in primary care settings, dementia remains under-diagnosed and undertreated, which warrants further improvements in this area [2,3].

Despite the imperative role of the family physicians (FPs) [also known as general practitioners (GP) or primary care physicians (PCP)] in the early diagnosis and management of dementia and representing the gatekeepers to specialists and to community support services [4], conflicting studies were published on the obstacles that may prevent FPs to diagnose and manage dementia optimally [5,6]. The challenges facing FPs on the diagnosis and management of dementia have been identified [7-13]. In recent years, there has been growing global commitment to a more proactive approach to dementia care, with FP being the center of such attention. In essence, experts repeatedly have recognized FP's central role in the provision of timely diagnosis, management, and support to dementia patients and care providers [14-16]. For example, the Canadian Consensus Conference on the Diagnosis and Treatment of Dementia recognizes that the typical presentations of the most common types of dementia can be accurately diagnosed and managed by FPs, even in the early stages of the disease [14,17]. Thus, further investigation could improve dementia detection and management in primary care settings, where current Canadian primary care system faces challenges in providing responsive, comprehensive, safe, and cost-effective dementia care [7].

To date, few studies have been undertaken to examine the views of FPs regarding diagnosing and treating dementia [18]. Many obstacles have been identified in the diagnosis and management of dementia in primary care settings [8,19,20] and the pros and cons to early detection and treatment of dementia in primary care settings remain controversial and subject of debates [18,21,22]. Additionally, although there is an positive change in the attitude of FPs [23], the lack of resources, such as access to specialists, brain imaging, social services, and community services, was also noted as a barrier [24-26].

Ongoing surveying of clinicians remains important in primary care settings even though the response rates are declining [27].

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Further investigation of the perceptions and attitudes of FPs regarding dementia diagnosis and clinical practice is important because, A) FPs are pivotal in facilitating early diagnosis, and their attitude affects practice; B) evidence shows that a considerable number of demented individuals are at home who were not known by their FPs [28], in other words, they are under-recognized, or under-presented; C) several guidelines [29-31] for the diagnosis and management of dementia has been proposed and thus concordance and view of the primary care physicians is imperative in ameliorating dementia care and to help identify the perceptions on the diagnosis and management of dementia [21]; D) data exist to suggest that about 50% of the physicians routinely withheld a dementia diagnosis [13]; E) poor awareness of general practitioners' knowledge of dementia diagnosis and management and its epidemiology leads to an over-estimation of caseload [20]; and F) this area of research have received limited attention in the past [32].

The few international studies examining the view of FPs on dementia care [18,20,23,25] used various study designs (e.g., randomized controlled trial, focused group interview), and differently captured FPs perspective on dementia care and clinical practice with various sample sizes (ranging from 28 [25] to 182 [18]). The international results are unequivocal [33,34], that to enhance dementia care, specific educational program is needed for the GPs, and that validated tools should be used in the future epidemiological studies. Current evidence has certain limitations and one is the lack of a validated measure to examine attitude and perspective of FPs on dementia care and associated clinical practice.

Thus the primary objectives of the present study were to A) develop and B) validate a self-report postal survey (questionnaire) to assess perception and practices attitudes of FPs on the diagnosis and management of dementia in Canadian primary care settings, specifically in New Brunswick, a Maritime bilingual province with approximately 754,000 in population, C) to explore factors that may facilitate or impede FP's ambulatory care.

## Methods

The development of the Family Physicians' Perception of Dementia Care (FPPDC) followed the guidelines proposed by Burns and colleagues [35].

### Item selection

Two experts with psychometric experience developed the FPPDC questionnaire. The goal of the questionnaire was to examine the attitudes and practices on the diagnosis and management of dementia in primary care settings. A list of 39 items was generated through a literature review, derived from survey questionnaires, and subsequently pilot tested with a FP as content expert.

Questions on attitudes were chosen and adapted from four previous questionnaires [18,20,25]. The items from Milne and colleagues [18] exploratory study included items measuring attitudes towards diagnosis. The items drawn from Turner and colleague's questionnaire [20] pertained to knowledge, confidence and attitudes regarding diagnosis and management of dementia. The items adapted from van Hout and colleague's questionnaire [25] covered perceptions, practice, and possible barriers to the diagnosis and management of dementia. A 5-point Likert scale (1 = disagree to 5 = agree) was used to indicate the level of agreement with each statement.

The questionnaire items pertaining to socio-demographic data collection were adapted from the Audit Questionnaire [36]. This section included information on FPs practice profile, such as number of patients with dementia, years of practice, practice setting (rural or urban) and the languages spoken by their patients. The present questionnaire was prepared in English and French following a rigorous back-translation process. The questionnaire was in black ink and used Times New Roman size 12. Specifically, the translation was undertaken by a bilingual researcher whose first language is French, with emphasis on conceptual rather than literal translations, and on clear and concise formulation. Two bilingual research team members

reviewed and edited the translation for consistency with the English version. Subsequently, the French items were back-translated by an independent bilingual individual whose native tongue is English. The initial and final English versions were then compared to confirm consistency. The questionnaire was administered in the language (French and English) chosen by the FPs.

## Procedure

Ethical approval was garnered from the *Comité d'éthique de la recherche avec les êtres humains* at the Université de Moncton. A brief cover letter detailing the study with accompanying questionnaires (both in English and French) was sent by mail (between September 2010 and February 2011) to all identified FPs currently practicing in New Brunswick, Canada. The FPs had the option of returning the responses either by fax or by mail.

In a second attempt to solicit FPs' participation, after 3 months, a follow-up letter with attached questionnaires was sent to non-respondents. The signed consent forms and completed questionnaires were returned to the principal investigator by fax or by mail. As a necessary part of policy-related research [37], to achieve high response rate, each FP was provided a financial inducement of 25\$ for participation.

Respondents' answers were coded and entered into an SPSS (version 22) database. Because of their low occurrence level (less than 5% per item), the "not applicable" or "don't know" answers were treated as missing data. The results obtained on the items evaluating attitudes and practices were subjected to a type of hierarchical cluster analysis, the Ward's method [38], with cut off point set at 5 [39] in order to reduce the number of items. Factor analysis using principal axis factoring with promax rotation was used to determine the validity of the factor structure of the FPPDC questionnaire [40] as well as a reliability analysis using Guttman indices [41]. Here, the percentages are rounded to the nearest ten.

## Results

The respondents on the 39 items questionnaire of this pilot study consisted of 80 FPs (10% response rate, 778 family physician received the survey), where 45% were practicing at urban and 55% rural settings. The FPs' number of years of practice varied; this was categorized into three groups. The majority (46%) had less than 10 years of practice, and the rest either had 10 to 20 years of practice (29%) or more than 20 years (25%). The English was the primary professional language (54%), followed by French (33%), and finally by bilingual services (14%). Sixty-four percent of the FPs estimated that 10% or more of their patients had dementia, while 15% of the FPs reported a percentage varying between 6 to 10% and even 21% estimated less than 5%.

The 39 items questionnaire was reduced to 23 items, first using exploratory factor analysis and second with a consensus between expert FP and research team. To this end, various level of agreement was obtained from the respondent FPs on the items of the questionnaire. The factor analysis reduced the number of items to 23 and identified seven categories (knowledge, available resources, screening practices, skills, referrals to specialists, facilitating attitudes, unfavorable attitudes) pertaining to the diagnosis and management of dementia. The proportion of FPs agreeing with the items of the questionnaire ranges between "Family physicians have a very limited role to play in the care of patients" (3.8%) and "I evaluate patients with dementia when a patient's relative thinks the patient might have dementia" (98.8%). Based on the observation of the percentage of FPs agreeing on the items, "screening practices" and "facilitating attitudes" has the highest endorsement (over 75%), ranging from 75-98.8%, and "available resources" and "unfavorable attitudes" the lowest endorsement, ranging from 3.8-28.8%. Table 1 shows the FPs agreement rate with the questionnaire items.

To see consistency between observation and quantitative methods, and to improve the quality of the questionnaire, items were subjected to two cluster analyses [39] and a subsequent factor

**Table 1:** FPs agreeing with the questionnaire items regarding diagnosis and clinical management of dementia (N = 80).

Questionnaire items	% of participants agreeing (Number of cases)
<b>Knowledge</b>	
1. I regularly keep up to date with the Canadian Consensus Conference on Diagnosis and Treatment of dementia (CCCDTD) guidelines.	36.2 (29)
<b>Available resources</b>	
2. In my practice setting, I have at my disposal good community services for patients living at home.	28.8 (23)
3. In my practice setting, I have at my disposal good community services for patients living at home for which the waiting time is acceptable.	21.2 (17)
4. In my practice setting, I have at my disposal good support services for carers of patients.	18.8 (15)
5. In my practice setting, I have at my disposal good support services for carers of patients for which the waiting time is acceptable.	12.5 (10)
<b>Screening practices</b>	
6. I evaluate patients with dementia when the patient seems to be forgetful.	95 (76)
7. I evaluate patients with dementia when the patient complains of forgetfulness.	95 (76)
8. I evaluate patients with dementia when a patient's relative thinks the patient might have dementia.	98.8 (79)
9. I am familiar with dementia diagnosis criteria.	86.2 (69)
<b>Skills</b>	
10. I feel confident that I have adequate skills to develop an adequate management plan for patients.	72.5 (58)
11. I feel confident that I have adequate skills to educate patients and their families.	71.2 (57)
<b>Referrals to specialists</b>	
12. I generally refer patients to a specialist for the management/treatment of dementia.	43.8 (35)
13. I generally refer patients to a specialist for the evaluation of dementia.	40.0 (32)
<b>Facilitating attitudes</b>	
14. Much can be done to improve the quality of life of caregivers.	87.5 (70)
15. Much can be done to improve the quality of life of patients.	87.5 (70)
16. It is important to diagnose dementia early on in its course.	85.0 (68)
17. Families would rather be told about their relative's dementia diagnosis as soon as possible.	78.8 (63)
18. Appropriate interventions can slow down the progression of dementia.	75.5 (62)
<b>Unfavorable attitudes</b>	
19. The management of dementia is more often frustrating than rewarding.	25.0 (20)
20. Diagnostic criteria are less important than my intuition in the diagnosis of dementia.	16.2 (13)
21. Providing a diagnosis is usually more harmful than helpful.	13.8 (11)
22. As long as effective treatment is absent, diagnosing dementia has no priority.	6.2 (5)
23. Family physicians have a very limited role to play in the care of patients.	3.8 (3)

**Table 2:** Results of the cluster, factorial and reliability analyses pertaining to the categories of questionnaire items (N = 80).

Categories of questionnaire items	Items	Explained variance (%)	Eigen value of first axis	Guttman
<b>Diagnosis and management of dementia</b>				
Knowledge	1	---	---	---
<b>Available resources</b>	<b>2, 3, 4, 5</b>	<b>60.95</b>	<b>2.44</b>	<b>0.87</b>
<b>Screening practices</b>	<b>6, 7, 8, 9</b>	<b>55.16</b>	<b>2.21</b>	<b>0.81</b>
Skills	10, 11	71.60	1.43	0.84
Referrals to specialists	12, 13	69.14	1.38	0.82
<b>Attitudes towards dementia</b>				
<b>Facilitating attitudes</b>	<b>14, 15, 16, 17, 18</b>	<b>61.80</b>	<b>3.09</b>	<b>0.88</b>
<b>Unfavorable attitudes</b>	<b>19, 20, 21, 22, 23</b>	<b>41.64</b>	<b>2.08</b>	<b>0.78</b>

**Note:** In bold, acceptable categories for the questionnaire given the number of included items.

analysis. The result of the first cluster analysis pertaining to the diagnosis and management of dementia yielded two significant constructs which are available resources and screening practices. The second cluster analysis pertaining to attitudes towards dementia yielded two significant constructs, which are facilitating attitudes and unfavorable attitudes. The results of both cluster analyses, relating to the diagnosis and management of dementia can be found in [table 2](#). The dendrograms (not showing here) using the Ward's method identified four significant domains: available resources, screening practices, favorable attitudes and unfavorable attitudes. The results of the Guttman analysis indicates good inter-item reliability for most of the items (> 0.80 score for most items) [42], with the exception of the item pertaining to "unfavorable attitudes" (Guttman score = 0.78). This last domain could be considered acceptable or a trend given that the average of the Guttman score for the domains is higher than 0.80. Thus, the number of items retained for this questionnaire is 18 items, which comprise of 4 domains to measure diagnosis and management of dementia in primary care settings.

The final version of the questionnaire as well as the scoring procedure can be found in [appendix A](#). The French version of the questionnaire is available through the principal author.

## Discussion

The current pilot study led to the development of the FPPDC, an 18-item questionnaire pertaining to FPs dementia-related perception of available resources, screening practices, facilitating attitudes and unfavorable attitudes. The provisional version of the FPPDC has acceptable psychometric properties, including inter-item reliability and construct-related validity as demonstrated by statistical analyses and items selection procedure. In addition, the FPPDC meets recommendations to increase response rate [43] for conducting epidemiological surveys, since the English version of the questionnaire includes fewer than 1000 words.

The proportion of FPs reporting on the different questionnaire items concur with concerns raised in previous studies. For instance, FPs are minimally aware of guidelines to screen and diagnose dementia [17]. The FPs agreed that the lack of community services is a barrier to appropriate dementia care [24,25]. In sum, FPs mostly report appropriate screening practices and they hold favorable attitudes towards dementia care.

Nonetheless, the results need to be interpreted cautiously and confirmed through further surveys in primary care settings across

the country. In addition, the FPs estimated that approximately 10% of their family practice consists of dementia patients. Their result appears to be an over estimate of caseload [20] which is attributed to the lack of knowledge about the prevalence of Alzheimer's disease.

In one study, GPs stated that diagnostic uncertainty during the early stages of dementia, embarrassment to conduct a cognitive examination and communicate the diagnosis, non-consulting patients and a lack of time were the hindering factor. Also, they showed discrepancy between the GPs' views of their tasks and their clinical practice regarding dementia care [25]. This result tends to be in accord with our observation that "Family physicians have a very limited role to play in the care of patients" (3.8%) and "I evaluate patients with dementia when a patient's relative thinks the patient might have dementia" (98.8%). Also, our result is consistent with previous studies that found few factors significantly predicting practice, A) a belief that there are benefits to patients from early diagnosis, B) a belief that negative outcomes may result from a failure to diagnose early and the accessibility of local support services [18].

By the same token, our result, the percentage of FPs agreeing on the items, "screening practices" and "facilitating attitudes" has the highest endorsement (over 75%), ranging from 75-98.8%, and "available resources" and "unfavorable attitudes" the lowest endorsement, ranging from 3.8-28.8% is consistent with another study reporting that GPs had limited confidence in their diagnostic skills and in management of behavioural and other dementia problems [20].

The fact that limited number of FPs replied to our pilot survey contradict the results of the American Academy of Family Physician using a 29-item questionnaire surveying FPs and concluding that FPs are highly involved in the assessment and care of patients with dementia, and only few are not fully engaged [44].

## Limitations

The current study is not without limitations; here are a few of the most important concerns. First, in the epidemiological context, the lower return rate signals the likelihood of differences between the FP responders and the non-responders. Also, it can be assumed that respondents were probably more involved in dementia management and more interested in the topic. Thus, replication of the study, potentially with larger sample, as we have stated earlier, is warranted. By the same token, larger sample size will allow further analyses, examining for the effect of confounding factors. Statistically examining and psychometrically developing evidence-based questionnaire could be cost-effective, and potentially increase the likelihood that future epidemiological studies will yield valid and homogeneous results.

Second, the current questionnaire should be optimized given that psychometric experts heterogeneously suggest that the bare minimum number of items per category should be 3 items [45] or at least 5 items under each domain [35]. Thus, based on the data presented, we could summarize the findings only in light of the four domains, including *available resources*, *screening practices*, *facilitating attitudes* and *unfavorable attitudes*.

Third, based on the presentation of the responses provided by the 80 FPs, it is possible that some of the items were either avoided or missed. This stipulates the following question, how many incomplete responses were present, and why? Hence, future studies are indispensable to examine the perception of the FPS across Canada and then compare throughout cities and provinces. Furthermore, future studies could further determine whether FPs practicing in the rural region differ from those in the urban area in terms of dementia attitude and practice, and to what degree.

Fourth, survey research can be useful to enhance clinical practice [35]. However, the low response rate can be a barrier in gathering representative sampling of respondents [45]. The present questionnaire provides a short format to enhance response rate. Although the available surveys are valuable instruments, many of them have limitations (e.g., they are too lengthily) [45]. Previous

studies have provided strategies to enhance response rate [37,46], and if taken together along our questionnaire, we could potentially capture an ameliorated perspective on FPs perception towards dementia care.

## Conclusion

Underlying the need for collaborative models of dementia care are the attitudes and perceptions of FPs and other health care professionals. Hence, pilot data from the FPPDC questionnaire becomes essential to help uncover the obstacles to change of service delivery and the willingness to adopt collaborative models. In brief, given the need for enhanced dementia care, the attitudes and practices of FP, whom are central players in the diagnosis and management of dementia, further exploration is indispensable. With the developed pilot questionnaire, we enhanced our understanding of the service and evaluated key constructs of dementia-care by FPs. These outcomes potentially have implications for other primary care providers.

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