Family physicians' perspectives on care of dementia patients and family caregivers

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ABSTRACT

OBJECTIVE To identify factors that facilitate or impede family physicians in ambulatory care of patients with dementia and the family caregivers of such patients.

DESIGN Explanatory qualitative analyses of focus group discussions.

SETTING Large, medium, and small urban; suburban; and rural family practices from various regions of the province of Quebec.

PARTICIPANTS Twenty-five family doctors whose practices had at least 75% ambulatory patients; of these patients, an estimated minimum of 20% were 65 years old or older and at least 2% suffered from dementia.

METHOD Physicians were recruited by telephone to be paid participants in their regions in focus groups studying aspects of dementia care in ambulatory settings. Grounded theory and constant comparative methods were used to explore data from 3 French-speaking focus groups and 1 English-speaking focus group.

MAIN FINDINGS Physicians were 72% male, had a mean of 21.3 years in practice, and spent about 87% of their professional time in office practice. An estimated 38.7% of their patients were 65 years old or older, and 5.6% of these patients had Alzheimer disease or related dementias. Physicians were comfortable caring for these patients and their family caregivers but thought much of this care should come from support services offered elsewhere. Physicians admitted they had little knowledge of these services and had little interest in acquiring information about them. Government-run, community-based health and social service centres were the “black boxes” to which they referred patients and their caregivers for any form of help. Inconsistencies in the services offered by these centres were noted.

CONCLUSION While family doctors are seeking a more seamless form of interdisciplinary dementia care, a large amount of that care comes from support services about which physicians are not well informed and are not interested in learning.

EDITOR’S KEY POINTS

• In previous studies, family caregivers of people with dementia reported that doctors did not adequately control symptoms and manage medications for patients or adequately provide emotional support and social services links for caregivers.

• When specifically asked about care of patients with dementia, most doctors in this study expressed confidence in their ability to provide such care but did not see themselves as the answer to most caregivers' problems.

• Physicians thought that the gradual shift toward caring for patients with dementia longer in the community created a clear increase in the “burden of care for the home and family.” These doctors, however, were generally unaware of the resources within their communities that were specifically oriented to the needs of caregivers.

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Points de vue de médecins de famille sur les soins aux patients déments et sur les aidants naturels

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RÉSUMÉ

OBJECTIF Cerner les facteurs qui aident ou gênent les médecins de famille (MF) dans les soins ambulatoires aux patients déments et l’appui à leurs aidants naturels.

TYPE D’ÉTUDE Analyse qualitative explicatrice de groupes de discussion.

CONTEXTE Établissements de médecine familiale dans des petites, moyennes et grandes villes ou banlieues, et des milieux ruraux, dans différentes régions du Québec.

PARTICIPANTS Vingt-cinq MF comptant au moins 75% de patients ambulatoires dans leur clientèle; au moins 20% de ces patients avaient 65 ans et plus, et au moins 2% souffraient de démence.

MÉTHODE Les médecins étaient rémunérés; ils ont été recrutés par téléphone afin de participer dans leur région à des groupes de discussion sur le traitement de la démence en contexte ambulatoire. On a utilisé les techniques de théorie ancrée et de comparaison continue pour analyser les données de 3 groupes de discussion francophones et d’un groupe anglophone.

PRINCIPALES OBSERVATIONS Les médecins, dont 72% étaient des hommes, avaient en moyenne 21,3 années de pratique et consacraient 87% de leur temps à la pratique en cabinet. Environ 38,7% de leurs patients avaient 65 ans et plus, et 5,6% d’entre eux souffraient d’Alzheimer ou de démence analogue. Les médecins étaient à l’aise pour prendre soin de ces patients et de leurs aidants naturels, mais ils estimaient que ces soins devraient être fournis en grande partie par des services d’aide d’une autre source. Ils reconnaissaient mal connaître ces services et étaient peu intéressés à en apprendre davantage à leur sujet. C’est aux centres locaux de services sociaux et sanitaires gouvernementaux qu’ils dirigeaient leurs patients ainsi que leurs aidants, pour toutes formes d’aide. On a signalé certaines disparités dans les services offerts par ces centres.

CONCLUSION Alors que les MF souhaitent une forme plus homogène de traitement interdisciplinaire de la démence, une bonne partie de ces soins provient de services d’aide que les médecins connaissent mal et qu’ils sont peu intéressés à connaître.

Points de repère du rédacteur

• Dans des études antérieures, les aidants naturels des patients souffrant de démence déclaraient que les médecins ne contrôlent pas bien les symptômes et ne gèrent pas adéquatement les médicaments du patient, en plus de ne pas fournir un support émotionnel aux aidants naturels et de ne pas leur indiquer les liens avec les services sociaux.

• Lorsqu’on les questionne spécifiquement sur les soins aux patients déments, la plupart des médecins de cette étude déclarent être capables de fournir ce service mais ne croient pas détenir la solution pour la plupart des problèmes des aidants.

• Les médecins croyaient que le fait que les patients déments demeurent maintenant plus longtemps dans le milieu naturel entraîne une nette augmentation du fardeau de soins pour la maison et la famille. En général, toutefois, ces médecins connaissaient mal les ressources locales capables de répondre spécifiquement aux besoins des aidants.
shift from “care in the community to care by the community” has resulted in family members providing at least 80% of the care necessary to keep relatives out of institutions. Care of people with dementia is particularly challenging, and the need for such care is projected to quadruple over the next 50 years. Caregiving is associated with increased morbidity and mortality among caregivers; up to 50% of caregivers of patients with dementia develop psychiatric symptoms during the course of their caregiving. Given that counseling and support programs for caregivers can help them care for patients longer and delay institutionalization of those for whom they care, health policy makers have advocated for activities that prevent community-based care from breaking down.

Family caregivers of people with dementia think doctors do not adequately control symptoms and manage medications for dementia patients or adequately provide emotional support and social services links for caregivers. For example, a Pan-American telephone survey of informal caregivers of patients with Alzheimer disease found that 68%, 72%, and 76%, respectively, reported receiving insufficient information from doctors on medications, patients’ abilities to do daily tasks, and support groups. Structured oral interviews of 86 undifferentiated Montreal family caregivers of seniors elicited similar concerns. Paradoxically, a mailed survey of 200 Montreal family doctors (response rate of 72%) practising in the area covered in the aforementioned study found that more than 94% thought they were generally meeting the needs of family caregivers of elderly patients. Nonetheless, a substantial proportion of these physicians indicated that they lacked knowledge about or confidence in community resources, and only 16.9% maintained office reference lists of community services that might benefit patients or caregivers.

Given a Canadian Consensus Conference on Dementia recommendation that family physicians have a prominent role in dementia care, we opted to explore aspects of that activity. The acronym ACROSS provided a framework for our inquiry: Assessment; Communication of diagnosis and pertinent information about Alzheimer disease; Referrals to memory clinics, neurologists, geriatric psychiatrists, and community and support services; Ongoing evaluation of patients’ status and management; Solutions to patients’ and caregivers’ problems; and Sensitivity to caregiver issues. Our objectives were as follows:

- to describe family doctors’ attitudes toward and experience with ambulatory care of patients with dementia and the family caregivers of such patients;
- to identify physicians’ needs in caring for these people;
- to assess physicians’ attitudes toward and office use of printed or electronic community resource materials for dementia care; and
- to explore doctors’ recommendations of community-based resources for patients with dementia and their caregivers.

**METHODS**

Family doctors in Quebec were recruited by telephone to participate in 90-minute focus groups designed to discuss care of Alzheimer disease or related dementias. Physicians were paid $300 to partially compensate for travel costs and the half-day absence from their practices. Ethics approval was received from the Research Ethics Review Committee of St Mary’s Hospital Centre in Montreal. To facilitate input from physicians from diverse settings, we recruited 2 groups of doctors from Montreal (1 French-speaking and 1 English-speaking) to represent large urban practices; 1 French-speaking group from Quebec City to represent medium-sized urban practices; and 1 French-speaking group from Chicoutimi and environs to represent small urban and rural practices.

Recruitment was outsourced to a company (P&S Research) with experience in identifying doctors for medical studies. It used a protocol and selection criteria established by the researchers and designed to generate a sample of family physicians with experience in ambulatory care of patients with dementia. Inclusion criteria targeted physicians who estimated seeing at least 75% of their patients in office settings and whose practices had a minimum 20% of patients 65 years old and older; at least 2% of the patients seen in office settings had to have Alzheimer disease or related dementias.

An explanatory qualitative research design was used to generate a range of opinions. We hypothesized that, as doctors rarely have the opportunity to discuss process of care issues among themselves, focus groups might give them a chance to voice opinions and might also stimulate opinions. In the absence of published consensus guidelines on optimal size for focus groups on family practice research (ranging from 4 to 12 participants, and more typically from 5 to 8 participants), we aimed for 6 to 8 participants per group.

Content for our focus groups was based on an Internet review of literature on primary care doctors’ management of patients with dementia, with particular attention to the needs and roles of family caregivers, and on input from the Caregiver Support Centre of

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the CLSC René Cassin (now Centre de santé et services sociaux Cavendish), a recognized Quebec resource for family caregivers. Our research team generated and pilot-tested an English-language focus group discussion guide, which was then translated into French and back-translated into English to ensure linguistic fidelity. A bilingual focus group leader (not part of the research team) was hired to facilitate the 4 groups within the respective communities. While the interview guide was designed to stimulate a specific flow of discussion, the moderator was mandated to go with the group discussion, then ensure that all topics had been appropriately covered.19

Focus groups were held in spring 2005. Consent forms signed by participants included confidentiality agreements not to later attribute opinions to specific people. Participants also completed a short questionnaire on personal and practice demographics and a single 5-point inquiry into their level of enjoyment of elder care (1 being “no enjoyment” and 5 being “extremely enjoyable”). Sessions were audiotaped for verbatim transcription and comparison with field notes taken by an independent observer hired for that purpose. Transcripts were later analyzed by an independent qualitative analyst using a grounded-theory approach.20 This qualitative approach, successfully used in another study of doctors’ care of cognitively impaired seniors,21 used a systematic set of ongoing and repetitive procedures to inductively develop an understanding of a concept or situation. These procedures identified key elements, coded them, constantly compared them with differing or evolving perspectives as the data were reviewed, then categorized the relationship of these elements to each other and to the situation being examined.

FINDINGS

Characteristics of participants

Table 1 shows the outcome of recruitment; 720 telephone calls were required to achieve the desired number of physicians per group. All 25 physicians who committed to participating actually did so, and their characteristics are summarized in Table 2. Doctors’ estimates of the average number of patients they saw monthly varied from 485 in Quebec City to 600 in Montreal. The objective of enlisting clinicians with experience in ambulatory care of patients with dementia appears to have been achieved, as doctors reported they had 10 to 25 encounters with Alzheimer patients per month and another 10 encounters with patients with other forms of dementia. The Montreal physicians estimated they had an average of 4 new dementia patients per month; physicians in Quebec City and Chicoutimi had only half that number. This variance aside, no differences were observed in the issues raised or attitudes of doctors from the various urban and suburban centres, but the presence of only 1 rural physician eliminated the opportunity for

Table 2. Characteristics of participants: N = 25.

<table>
<thead>
<tr>
<th>PHYSICIAN GROUP</th>
<th>FREQUENCY OF PARTICIPANTS BY SEX (MALE/FEMALE)</th>
<th>MEAN NO. OF YEARS IN PRACTICE</th>
<th>MEAN % OF TIME IN OFFICE PRACTICE</th>
<th>MEAN % OF PATIENTS ≥65 Y</th>
<th>MEAN % (RANGE) OF PATIENTS WITH ALZHEIMER DISEASE AND RELATED DEMENTIAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Montreal physicians (N = 13)</td>
<td>9/4</td>
<td>15.6</td>
<td>89</td>
<td>37.0</td>
<td>5.5 (2-12)</td>
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<td>• English-speaking (n = 6)</td>
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<td>• French-speaking (n = 7)</td>
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<td>• Urban (n = 12)</td>
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<td>• Suburban (n = 1)</td>
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<td>Quebec City physicians (N = 6)</td>
<td>4/2</td>
<td>21.2</td>
<td>86</td>
<td>38.0</td>
<td>5.5 (2-16)</td>
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<tr>
<td>• French-speaking (n = 6)</td>
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<td>• Urban (n = 2)</td>
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<td>• Suburban (n = 4)</td>
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<tr>
<td>Chicoutimi physicians (N = 6)</td>
<td>5/1</td>
<td>27.2</td>
<td>86</td>
<td>41.0</td>
<td>5.8 (5-10)</td>
</tr>
<tr>
<td>• French-speaking (n = 6)</td>
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<td>• Urban (n = 4)</td>
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<td>• Rural (n = 1)</td>
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<tr>
<td>All physicians</td>
<td>18/7</td>
<td>21.3</td>
<td>87</td>
<td>38.7</td>
<td>5.6 (2-16)</td>
</tr>
</tbody>
</table>
Facilitators of care

Systemic factors that made dementia care easier included the presence of geriatric or specialized centres (in urban communities), specialists or consultants, physiotherapists, occupational therapists, social workers, and nurses, along with access to government-run, community-based health and social service centres, the CLSCs. Patient-related factors included patients and families who had some understanding of dementia, who had the ability to pay for private services or care, and who were “supportive, understanding, or accepting.” The consensus was that most families accept the diagnosis of dementia and work constructively on future care. Having an identified family spokesperson to coordinate communication and care between doctors and family was also seen as a strength.

Obstacles and challenges to care

Doctors reported difficulty in making diagnoses when patients had comorbidities. Initiation of care and family cooperation were sometimes problematic when the diagnosis was unclear. While follow-up of patients with dementia was generally perceived as “routine,” coordinating patient and family needs was not as straightforward and, therefore, dementia was viewed as a very time-consuming “involved illness.” This was especially the case when patients had no support network, when the stage of the disease did not justify long-term care, or when services offered by various CLSCs were inconsistent. Doctors in small centres felt hampered by insufficient expertise and consultation in neurology, geriatrics, and psychogeriatrics, while those in the larger centres wanted quicker and simpler access to consultants in these areas.

Commonly identified practice stressors included differences of opinion among patients, families, and doctors about competency to drive or about home versus institutional care. The amount of paperwork required was also a great concern (eg, powers of attorney, living wills, testaments, driving aptitude forms, and the semi-annual or annual “médicament d’exception” forms necessary to justify government payment for acetylcholinesterase inhibitors). The absence of clear guidelines on managing such issues was a frequently cited obstacle. To assist with these and other challenges in dementia care, doctors expressed a desire for more problem-based and case-based education on Alzheimer disease led by psychogeriatricians and social workers, and not “the endless talk about medication that is repeated by pharma companies.”

Perceptions of family caregivers’ needs

Physicians thought that the shift to greater dementia care in the community created an “increased burden of care for the home and family.” They perceived that caregivers needed more and quicker access to home care supports, day centres, respite care, patient sitters or attendants, Meals on Wheels, transportation services, legal assistance for administrative affairs (eg, wills, competency certificates), emotional help (support groups, activities, contacts with peer families), and advocacy. Doctors, however, were generally unaware of resources within their communities that were specifically oriented to the needs of caregivers.

Solutions for caregivers

Doctors did not see themselves as the answer to most caregivers’ needs. They thought the “CLSC system was the resource for patient care,” and they referred virtually all dementia patients (particularly those with deterioration or complications that could not be followed in office settings) to CLSCs. Such services were generally seen as reliable and somewhat team-based, but inconsistent in breadth, quality, or comprehensiveness of response. Because some cases had longer response times than doctors thought appropriate, physicians recommended having an easier referral system or an accessibility pathway that was less tedious (ie, one with less paperwork or faxing) and promoted regular, efficient feedback. The doctors thought a “24/7 1-800 number would be useful as a centralized source of expertise on dementia,” in which each patient had an identified case manager. They thought this might reduce “gaps in services” for patients and families by providing a “broad seamless system” that offered patient and family education, needs assessment, home assistance, hospital admission, continuity of care, and information for health professionals.

Use of community resources

Physicians were somewhat aware of organizations such as Alzheimer societies, were less aware of what these societies do, and rarely referred patients or families directly to them. Those in need were referred instead to CLSCs because “they know best what is available.” The doctors’ offices did not maintain any substantive or up-to-date lists of community resources, handouts, or pamphlets for patients or families. A few participants said, “I don’t... it’s not my job. I have no time. It is not my mandate.” Others said, “We may receive some literature when a program starts, but then we receive nothing after that to remind us about it, or changes that have occurred to it.” The doctors felt strongly that community information in “e-format” would not be helpful (“though the younger generation of physicians will use it more”). Consistent with this viewpoint, only about half the practitioners had office computers (and had little time for them). When they did have computers, they were most
commonly used for billing provincial health care plans. Overall, the doctors were not comfortable with e-mail, websites, search engines, or CD-ROMs.

DISCUSSION

Fundamentals of dementia care

Given published guidelines and consensus statements on recognition and treatment of dementia, it is notable that relatively little research has been published on the process-of-care issues surrounding it. We observed doctors’ concerns about limited or slow access to specialist consultations. While such constraints on dementia care have been described in Australia, France, Spain, Italy, and the United Kingdom, our finding that experienced physicians (professing to have good knowledge about dementia care) desired more specialist input might be seen as paradoxical. We hypothesize that this is indicative of the complexity of dementia care, or alternatively that doctors might be responding to patients’ or families’ need for input from more “authoritative” clinicians, much in the way some cancer victims consider seeking second opinions from major oncology centres. Such hypotheses are somewhat substantiated in the report of Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia, which identifies diagnostic uncertainty (after initial assessment, or treatment problems or failure) or response to a specific request by a patient or family as a second opinion as reasons for primary care doctors to consider referral to specialists in dementia care.

Community services referrals

Physicians are well placed to refer patients and families to organizations that provide education on and services for care of patients with dementia. The Third Canadian Consensus Conference recommends primary care doctors regularly inquire about caregiver needs and health and that physicians refer all consenting patients or families to Alzheimer societies. Our study found that doctors rarely referred caregivers to Alzheimer associations. Similar findings have been reported in American midwestern primary care, and Canadian academic family doctors are reported to refer only 13.1% of family caregivers of dementia patients for support and counseling. Such findings suggest serious gaps in dementia care by primary care doctors.

Caregiver factors affecting community referrals

For some family members, caregiving becomes a “career.” Models of informal or family caregiving, therefore, recognize a longitudinal course as well as temporal components influenced by length of illness, duration and nature of caregiving, and changes in the clinical status of patients. Evolving caregiving experiences can make it difficult for doctors to predict when caregivers will be open to their input. Factors that might affect receptivity include the degree of confidence, trust, and credibility established during doctor-patient-caregiver encounters; the functional status of patient and caregiver; families’ beliefs about their responsibilities and the involvement of outsiders; doctors’ and families’ awareness of the range of services available and what might be appropriate at any particular time; doctors’ evaluation of the readiness of patients and families to consider new options for care; and perceptions of the quality or appropriateness of community services. The outcome of the interplay of such variables has been described in a cross-sectional study of 608 caregivers (average participants had more than 5 years of caregiving) of community-dwelling patients with dementia randomly drawn from the New York State Alzheimer’s Disease and Other Disorders Registry (representing all types and stages of dementia). Only 203 participants (33%) responded positively to offers of referral for education to an Alzheimer association, referral for health care services, or access to human services.

Physicians’ interventions

Given the unpredictability of caregiver receptiveness to offers of help, our study doctors’ reluctance to be knowledgeable about community resources or to counsel on them might reflect their belief that such activity is not worth their time. It might be worthwhile, therefore, to identify situations where interventions might be cost-effective. For example, 1 population perhaps worth targeting is caregivers (especially spouses) of elderly people who have had recent emergency room visits, as those events appear to be associated with a decline in such caregivers’ general health and physical functioning. Studying experience with, and the nature of, coordinated care might help to identify what works and what does not, and thus provide a stronger rationale for specific interventions on behalf of caregivers.

Toward integrated care

Lack of familiarity with, or inappropriate use of, community services could be the most frequent obstacle to longitudinal dementia care. For example, a United Kingdom study by the Birmingham Social Services Department found that despite the availability of relatively large amounts of community information and initiatives for caregivers, there was little systematic approach to their use.

In our study, the doctors’ approach of using a “blanket” method of undifferentiated, nonspecific referrals to CLSCs thus might contribute to an uncoordinated approach to care of patients with dementia. One explanation for this type of referral might lie in “dementia-ism,” wherein a negative bias toward people with cognitive limitations might prompt doctors to try to rapidly transfer as much
care as possible to others. A second explanation might lie in the sense of inadequacy or discomfort some doctors feel when they struggle with failure of their skills to help people with whom they have often had long-standing meaningful relationships. This has been described as the difficulty of shifting from “curing” to “caring.” A third explanation might be that although doctors recognize the value of interdisciplinary teams in successful geriatric care, their own lack of knowledge of, attitudes toward, or skills for such collaboration might prompt rapid blanket referrals.

The doctors’ desire for geriatric care based on a seamless continuum was, notwithstanding some reservations about the consistency of care provided in CLSCs, seen as being best available at CLSCs. Their lack of familiarity with CLSCs might have been the result of uncoordinated or absent feedback about their patients and hence thought of CLSCs as black boxes. Because doctors commonly update their knowledge of patients through written or verbal consultations from colleagues, perhaps CLSCs need to improve their follow-up communication to physicians.

Practice-based obstacles to care

American Medical Association guidelines for managing dementia in primary care recommend that office practices have a staff member who has expertise in community resources and can link patients and caregivers to such services. In France, a survey of 435 general practitioners on care of seniors and family caregivers found that as these doctors were aware of their weakness in responding to caregivers’ administrative or social questions, 82% and 90% of them, respectively, saw lists of financial and social and home care services as “useful.” It was not clear, however, in whose hands such lists should best be, as 80% and 86% of doctors, respectively, identified social service and paramedical professionals as the most appropriate people to inform and counsel caregivers.

In comparison, our study doctors did not feel obliged to maintain accurate, current information on community resources, perhaps because the American guidelines are not practical for traditional Canadian solo or small group family practices. The recent promotion of large primary care group practices, integrated networks, community health groups, and so on, however, might mean that the recommendation of the Third Canadian Consensus Conference to have practice-based expertise on community resources might become more realistic because expanded groups tend to be more dependent on computer technologies—a factor that has been identified as a facilitator of complex geriatric care.

Limitations

Purposive sampling, by its selective nature to ensure recruiting people who meet desired characteristics, imposes more stringent inclusion criteria and makes recruitment more challenging. It resulted in us successfully attracting a cohort of experienced clinicians, but the absence of doctors less involved in dementia care or of younger practitioners might have excluded doctors with different practice styles or philosophies of care. Also, our recruiting method was not robust enough to get representative participation from rural doctors, a problem frequently noted in focus group research. Future research is needed, therefore, to address this general recruitment issue, and to better study care of patients with dementia in rural settings.

Concern might be expressed about the large number of telephone calls necessary to get the desired number of doctors from within the targeted communities. Such challenges in recruiting community-based physicians to health services research have been well described, with broad recruitment rates (often using noncomparable denominators) ranging from 2.5% to 91%. Highest success has been reported when research topics were of particular interest to potential participants and when recruiters were personally known to them. Recruiting people known to the researchers might be inadvisable in focus group research, however, given the potential risk of approaching those of like mind. Another limiting factor in specifically recruiting for a focus group (as opposed to a survey or patient enrolment from doctors’ practices) is that the former requires participants to be available at a certain time and place, which again limits the available participants.

In searching the literature to establish a benchmark against which our recruiting rate might be compared, we found the closest comparable study was a qualitative study on care of patients with dementia using face-to-face interviews of primary care doctors in Omaha, Nebraska. While that study approached roughly 4 times fewer physicians than we did to recruit a sample 20% smaller than ours, a major difference was that it took all comers, as they imposed no inclusion criteria. As well in our study, we believe that some doctors might have expressed “no interest” to rapidly curtail the telephone call once they realized they did not meet our inclusion criteria.

Finally, the Omaha group did not report on the actual number of telephone calls made or the number of unreachable doctors. In our study, given a much larger number of doctors to call, the telephone solicitors did not make many repeat calls if there was no answer, there was a persistent busy line, or the office secretary responded on behalf of the doctor. Such differences would appear to justify the number of telephone calls needed to generate our sample.

Conclusion

Family physicians experienced in care of people with dementia and their family caregivers are comfortable...
with this role. They perceive their input to be only a small part of what these patients and caregivers need and seek easier access to collaboration from specialists. Much of what patients and families require, however, comes from community support services. Doctors are not well informed about these community support services, and they do not seem to want to find out more about them.

Contributors
All the authors contributed to concept and design of the study, protocol development and implementation, and interpretation of findings. Dr Yaffe did the literature review and wrote all drafts of the article. Ms Orzech and Ms Barylak contributed to the intellectual content of the study and editing the manuscript, and approved the final version of the article submitted.

Competing interests
This project was supported by a grant from Pfizer Pharmaceuticals Canada. The project was initiated solely by the authors. The funder had no input into any aspect of study design or implementation or into data analysis or interpretation.

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References
2. Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national pro-
3. Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan and others. The funder had no input into any aspect of study design or implementation or into data analysis or interpretation.

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2. Toghill PL, Putnam W. Group interviews in primary care research: advancing the state of the art or ritualized research? Fam Pract 2002;19(3):278-84.

Research

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