Family physicians and dementia in Canada

Part 1. Clinical practice guidelines: awareness, attitudes, and opinions

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ABSTRACT

OBJECTIVE To assess Canadian family physicians' awareness of, attitudes toward, and use of the 1999 Canadian Consensus Conference on Dementia (CCCD) clinical practice guidelines (CPGs); to explore the barriers and enablers to implementing dementia CPGs in clinical practice; and to identify more effective strategies for future dementia guideline development and dissemination.

DESIGN Qualitative study using focus groups.

SETTING Academic family practice clinics in Calgary, Alta, Ottawa, Ont, and Toronto, Ont.

PARTICIPANTS Eighteen family physicians.

METHODS Using a semistructured interview guide, we conducted 4 qualitative focus groups of 4 to 6 family physicians whose practices we had audited in a previous study. Transcripts were coded using an inductive data analytic strategy, and categories and themes were identified and described using the principles of thematic analysis.

MAIN FINDINGS Four major themes emerged from the focus group discussions. Family physicians 1) were minimally aware of the existence and the detailed contents of the CCCD guidelines; 2) had strong views about the purposes of guidelines in general; 3) expressed strong concerns about the role of the pharmaceutical industry in the development of such guidelines; and 4) had many ideas to improve future dementia guidelines and CPGs in general.

CONCLUSION Family physicians were minimally aware of the 1999 CCCD CPGs. They acknowledged, however, the potential of future CPGs to assist them in patient care and offered many strategies to improve the development and dissemination of future dementia guidelines. Future guidelines should more accurately reflect the day-to-day practice experiences and challenges of family physicians, and guideline developers should also be cognizant of family physicians' perceptions that pharmaceutical companies' funding of CPGs undermines the objectivity and credibility of those guidelines.

EDITOR'S KEY POINTS

- Clinical practice guidelines (CPGs) can standardize and improve the quality of care, increase accountability, and conserve resources. Although CPGs are widely available, evidence suggests that family physicians do not follow them. This study used focus groups to explore family physicians awareness of, attitudes and opinions about, and use of the 1999 Canadian Consensus Conference on Dementia (CCCD) CPGs.
- Most of the participants in this study were not aware of having received the CCCD CPGs. Those who did remember receiving them did not have much knowledge about the specific content. There was disagreement about where guidelines fit in the "evidence hierarchy," and many participants were concerned about the credibility of the CCCD CPGs because they were funded by pharmaceutical companies.
- Some participants were also concerned about the relevance of CPGs; many believed that family physicians (and possibly patients and family caregivers) needed to be more involved in preparing future guidelines. They also suggested that guidelines would be more widely used if they were available in a variety of formats, including concise "1-pagers" and electronic versions.

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Le médecin de famille canadien face à la démence

Première partie : Lignes directrices pour la pratique clinique : sensibilisation, attitudes et opinions

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RÉSUMÉ

OBJECTIF Évaluer le degré de sensibilisation des médecins de famille canadiens aux lignes directrices pour la pratique clinique (LDPC) de la Conférence canadienne de consensus sur la démence (CCCD) de 1999, leur attitude à leur égard et l'utilisation qu'ils en font, déterminer les facteurs favorables ou défavorables à l'application de ces LDPC dans leur pratique; et cerner des stratégies plus efficaces pour l'élaboration et la diffusion des futures directives sur la démence.

TYPE D'ÉTUDE Étude qualitative à l'aide de groupes de discussion.

CONTEXTE Cliniques universitaires de médecine familiale de Calgary (Alberta) et d'Ottawa et Toronto (Ontario).

PARTICIPANTS Dix-huit médecins de famille.

MÉTHODES À l'aide d'un guide d'entrevues semi-structurées, on a tenu 4 groupes de discussion qualitatifs regroupant 4 à 6 médecins dont nous avions vérifié la pratique dans une étude antérieure. Les transcriptions ont été codées par une analyse stratégique inductive des données, et les thèmes et catégories ont été identifiés et décrits selon les principes de l'analyse thématique.

PRINCIPALES OBSERVATIONS Quatre thèmes principaux sont ressortis des discussions. Les médecins de famille 1) connaissaient très peu l'existence et le contenu précis des lignes directrices de la CCCD; 2) avaient des opinions claires sur les buts des lignes directrices en général; 3) se disaient très préoccupés par le rôle de l'industrie pharmaceutique dans le développement de ces lignes directrices; et 4) avaient plusieurs suggestions pour améliorer les futures lignes directrices sur la démence et les LDPC en général.

CONCLUSION Les médecins de famille connaissaient très peu les LDPC de la CCCD 1999. Ils reconnaissaient néanmoins que les futures LDPC pourraient les aider à traiter leurs patients, et suggéraient plusieurs stratégies pour en améliorer l'élaboration et la diffusion. Les futures lignes directrices devraient refléter plus étroitement les expériences de pratique et les défis quotidiens des médecins de famille; et il faudrait aviser les responsables des lignes directrices que les médecins de famille estiment que le fait que des compagnies pharmaceutiques les financent nuit à l'objectivité et à la crédibilité des LDPC.

POINTS DE REPÈRE DU RÉDACTEUR

- Les lignes directrices pour la pratique clinique (LDPC) peuvent standardiser et améliorer la qualité des soins, augmenter la responsabilité et préserver les ressources. Même si les LDPC sont facilement disponibles, les données laissent croire que les médecins de famille ne les observent pas. Cette étude s'est servi de groupes de discussion pour évaluer le degré de sensibilisation, les attitudes et les opinions des médecins de famille à l'égard des LDPC sur la démence de la Conférence canadienne de consensus sur la démence 1999 (CCCD), et l'utilisation qu'ils en font.
- La plupart des participants de l'étude ignoraient avoir reçu les LDPC de la CCCD. Ceux qui s'en souvenaient en connaissaient peu le contenu. On ne s'entendait pas sur la place de ces directives dans la hiérarchie des données probantes, et plusieurs participants s'inquiétaient de la crédibilité des LDPC de la CCCD, subventionnées par des compagnies pharmaceutiques.
- Certains participants se préoccupaient aussi de la pertinence des LDPC; plusieurs croyaient que des médecins de famille (et peut-être aussi des patients et des aidants familiaux) devraient participer davantage à l'élaboration des futures LDPC. Ils ont dit aussi que les directives pourraient être plus largement utilisées si elles étaient disponibles sous plusieurs formats, y compris des versions électroniques ou des abrégés d'une page.

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Clinical practice guidelines (CPGs) have been identified as a way to overcome variations in family physicians' practices by standardizing and improving the quality of care. They can also increase accountability, conserve resources, and provide transparency for patients.[1] Guidelines have been developed and applied to all aspects of care, including referral, prescribing, management of specific diseases, and preventive care. Some guidelines, including the CPGs from the 1999 Canadian Consensus Conference on Dementia (CCCD), incorporate all of these aspects of care. The CCCD CPGs make 48 recommendations, including recommendations about early recognition, the importance of careful history and examination in making a positive diagnosis, essential laboratory tests, and many more.[2]

In spite of the widespread availability of CPGs, there is evidence that family physicians do not follow them.[3,4] In a recent study, we found that family physicians' compliance with the CCCD recommendations was highly varied; from fair to good for the assessment of dementia, but poor for the assessment of caregiver coping and driving safety.[5] Evidence shows that CPGs alone are not sufficient for improving the quality of care, as the dissemination of guidelines has limited effect on their implementation.[6]

A number of earlier studies sought to understand why family physicians do not closely follow guidelines[7,8] by focusing mainly on the development and implementation of CPGs.[4] Yet few studies have explored family physicians' views on guidelines and the barriers to implementing guidelines in daily practice.

Langley et al conducted in-depth interviews with British GPs.[7] They discovered that the use of practice guideline information is complex and that "guideline implementation occurs in the context of conflicting pressures for clinical autonomy and professional standardization and quality improvement."[7] A study of why GPs might not implement evidence-based guidelines in their clinical practice revealed several barriers.[8] These included doubts about the applicability of trial data to individual patients; ageist attitudes of some GPs; the effects of time pressure and financial considerations; the absence of effective computer systems; and the absence of educational mentors.[8]

It has been estimated that the average family physician has 20 to 40 patients with dementia in his or her practice and 4 to 8 new patients developing dementia each year.[9] Given the clinical burden and the complexity of dementia, family physicians will likely have to rely on some form of CPGs to assist them in providing dementia care.

The purpose of this study was to assess Canadian family physicians' awareness of, attitudes toward, and use of the 1999 CCCD CPGs (the study began before the most recent version of the CCCD guidelines were published in 2006); to explore ways in which dementia CPGs acted as barriers and enablers in family physicians' practices; and to identify more effective strategies for future dementia guideline development and dissemination.

METHODS

Study design and sample

A qualitative focus group format was used. Using focus groups is an effective way to capture communication between respondents and to examine their attitudes, values, and understanding in a particular area,[10] while also maximizing resources. Criterion sampling was used.[11,12] The inclusion criterion was that family physicians had to practise at 1 of the 6 university-affiliated clinics that were assessed in our previous chart audit study (3 clinics in Calgary, Alta; 1 in Ottawa, Ont; and 2 in Toronto, Ont).[5] Eighteen (7 male and 11 female) out of a possible 34 family physicians who participated in the previous study formed the focus groups, which were conducted in meeting rooms at 3 of the clinics.

Data collection

Interviews were conducted by trained facilitators using a semistructured interview guide. All groups were audiotaped and the recordings were transcribed verbatim. Research ethics approval was granted by the 3 universities affiliated with the clinics.

Data analysis

Data were analyzed using iterative thematic analysis[13,14]: 1) becoming familiar with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. An inductive approach was taken, meaning that the research team did not enter into data analysis with preconceived theoretical frameworks; instead, they allowed the themes to emerge from the participants' dialogue and group interaction.

The principal investigator (N.P.) listened to the audiotapes while simultaneously reading the transcripts to verify quality and to become familiar with the data. Transcripts were circulated among the entire research team for their input and familiarization with the data. The principal investigator and another research team member (M.P.) engaged in initial coding. Using a table, quotes were entered alongside illustrative codes organized by the interview guide questions. Coding facilitated the process of finding themes and categories. Using the facilitators' field notes, attention was given to group dynamics, including disagreements, mutual reinforcements, and humour.[10]

After reading the transcripts and coding the data according to its content, several themes were evident. Research team members assessed agreement on codes and later reviewed the themes emerging from the data, checking for whether or not the coded extracts illustrated the themes. After clarifying meanings through discussions over teleconferences and in writing, all research team members agreed on naming and defining the themes. Researchers were satisfied that saturation was reached when no new themes were identified from the transcripts. The final report was a collaborative effort among the entire team to select the most compelling extracts to relate back to a discussion on CCCD guidelines. Respondents are identified by letter and focus group number.

FINDINGS

Four main themes about guidelines emerged during the focus groups as outlined below.

Awareness

Most participants were not aware of having received the CCCD guidelines with the *Canadian Medical Association Journal* in 1999. Less than half recalled seeing them or reading them after they were first disseminated. Those who did recall reading them were unfamiliar with the specific content of the guidelines. Other sources of information about dementia specified included the National Guideline Clearinghouse, medical residents, drug companies, and serendipitous discovery during literature searches.

Respondents' specific lack of awareness of these guidelines was reflected in comments like the following:

> I don't have them in my office that I'm aware of and don't really know what's there. (B4)

> [I have] heard of them, probably have them buried here somewhere, but can't find them. (C4)

> I think that there are a few that I refer to constantly like the lipid guidelines and there are some that, yes, I know that they exist, and I've read them when they initially came out and they're not part of my everyday practice. (C1)

In spite of not knowing about the existence or the content of the guidelines, family physicians reported that they did know how to access the dementia CPGs if they thought they needed to.

Participants who were aware of the CCCD guidelines recalled that epidemiology, assessment and screening, assessment tools (eg, Mini-Mental State Examination, clock diagram), diagnosis, treatment, definitions of types of dementia, diagnostic tests (eg, bloodwork, computed tomography), and driving assessment were mentioned.

Purpose

Family physicians expressed differing opinions about where to place CPGs in their "evidence hierarchy." Because most of the participants were not aware of the CCCD guidelines, and the few who were had limited knowledge of their contents, the discussion about the purpose of guidelines was framed in general terms. Physicians thought that guidelines varied in quality. While some participants saw them as lower on the evidence hierarchy than the results of randomized controlled clinical trials, others saw them as being higher:

> [P]ractice guidelines include evidence from the randomized controlled trials, so my idea of it is that somebody with the time to review all of the evidence comes up with a summary and a recommendation based on that, which saves me from having to do it myself, which I would never have the time to do. So, I thought it was higher, because it wasn't just 1 randomized trial, but it was almost like a meta-analysis of them. (B1)

Furthermore, while some viewed CPGs as "well-informed suggestions" (B3) (ie, guidance), others saw them as reflecting a standard of care to be followed (ie, prescription):

> I sort of view it as expert opinion that provides a clinician with a guide with regards to the standard of care, so what would the majority of physicians do in terms of providing care? So not necessarily a gold standard and not necessarily something that you have to abide by, but generally providing you with a standard of care that you want to sort of achieve or attain ... and I know that they do look at randomized controlled trials, but I sort of see it as expert opinion. They gather experts who review the data and sort of come up with what they consider the standard of care. (C1)

Others expressed the view that guidelines provided an informational resource that became less useful as familiarity with that knowledge increased through frequency of use:

> I view them as a cookbook ... here's a way of doing it. It's usually only one approach. It's completely contextually based, and it may or may not be relevant to what we're doing. The less I know about a condition the more helpful guidelines are. The more I know, the less I need to refer to them basically because I incorporate them into my practice. (B1)

Influences, bias, and industry

Those physicians who were aware of the CCCD guidelines and had some knowledge of their contents expressed substantial concerns or suspicions about the legitimacy of guidelines because of the perceived influence of pharmaceutical companies on the development and promotion of guidelines.

> There was a big push that anyone who has any kind of diagnosis of dementia should be on medications early on—there was that big push. (J2)

> That's where the pharmaceutical companies … get really excited about this and the real potential number of elderly and the amount of money to be made, so any small trial that showed any small improvement was picked up and pounded over our heads … and later [studies] have shown that [the results have] not been as exciting as they originally were. (N2)

Ideas and recommendations for the future

Several participants offered suggestions to improve future guideline development, dissemination, and use in family medicine. The idea that guidelines should be available in concise and varied formats was echoed numerous times:

> [Guidelines should be] something on 1 page instead of a book that … gets filed on a shelf. (B1)

> I think that all physicians access information in different ways. You've spent all this time developing the guideline: to get the biggest bang out of that is to have multiple types of formats. To have a little type of summary on a plastic card. To have it as a mail-out. To have it available on a webpage. To have it on the Alzheimer's site. (C1)

Family physicians described being inundated with guidelines and there was considerable overlap between some guidelines (eg, cardiovascular disease and dementia guidelines). To this end they called for greater "synthesis" between related guidelines; they should be interchangeable and dynamic to improve efficiency:

> So the task is how to synthesize and how to do it effectively? So do some of them have overlapping questions? Like someone has to almost look at these and say, okay, well what is overlapping in these guidelines? Luckily diabetes and hypertension have a lot of overlap … some of this stuff overlaps, but you don't see very much … synthesis of guidelines. (B2)

One explanation for this suggestion is the experience of "guideline fatigue": "I guess my personal opinion is I'm sort of at some point 'guidelined out,' like you know as far as hypertensive guidelines are concerned." (C1) One family physician commented that given the number of clinical practice guidelines, "If we get too many, we get muddled." (B3)

There was also a desire to see greater inclusion of family members of patients with dementia in the guideline development process:

> If you asked family or if that's even important, I'm not quite sure, as to what they see as barriers to help, you know, managing the health of their loved ones. Sometimes that can be a wealth of information. Like you hear about Nancy Regan publicly speaking about taking care of Ronald Regan or you hear certain people speaking on challenges they've had to face. So I think in terms of framing the care that we provide that sometimes that may be useful … to see when you're developing them if you can have some input. (C1)

Many participants believed very strongly that guidelines were developed by people who had little knowledge or understanding of the "lived experience" of family physicians and that guidelines should be developed by individuals and groups more familiar with day-to-day family physician practice:

> This is real-world stuff and it's all airy-fairy written about and then we have to take all of this stuff and apply it and it doesn't work. It *needs* people who are on the ground doing the work to say, "You expect me to do that! In the context of office visits, you've got to be out of your mind!" (B2)

> They're usually never completely relevant because they're mainly processes or approaches that are really not appropriate in our setting, or not accessible in our setting. (B1)

DISCUSSION

In a previous study, we identified that family physicians' compliance with the 1999 CCCD CPGs varied from fair or good (for medical assessment of the condition) to poor (assessment of caregiver coping and driving safety).[5] Rather than follow the dominant approach of framing the problem in terms of a lack of guideline implementation by family physicians or "as doctors failing to follow guidelines,"[7] we sought to explore experiences of guidelines from the users' perspective, using the CCCD guidelines as an example.

Cabana et al[4] have identified categories of barriers to guideline adherence by physicians. These include *knowledge-related barriers* (lack of awareness, lack of familiarity), *attitude-related barriers* (lack of agreement with specific or general guidelines, lack of outcome expectancy, lack of self-efficacy, and lack of motivation or inertia of previous practice habits and routines), and *behaviour-related barriers* (environmental factors such as lack of time or resources, organizational constraints, etc). This is a useful framework for understanding our results.

Similar themes have been identified in previous research,[4] but several strong themes emerged from our study that have been only partly explored elsewhere.

Awareness

Lack of awareness or familiarity with CPGs has been previously identified as a barrier to physician adherence to CPGs in relation to behaviour change.[4] This theme of lack of awareness of the 1999 CCCD CPGs was observed in our study. Less than half of our 18 participants stated that they were aware of the CCCD guidelines and their specific contents. It is not clear whether this low level of awareness was due to antipathy to guidelines in general, dissatisfaction with the dementia guidelines in particular, indifference to the topic itself, or an ineffective dissemination strategy. Some participants had a clear antipathy to the CCCD guidelines due to a perception of pharmaceutical industry bias.

An important factor contributing to lack of awareness could be an ineffective passive dissemination strategy. The guidelines were mailed with the bimonthly issue of the *Canadian Medical Association Journal*, which is clearly not an effective way to deliver future guidelines to family physicians.

Purpose

A second main theme to emerge from our data concerns the different perceptions family physicians have of the general purpose of CPGs. This theme falls under the category of *attitude-related barriers*.[4] Because the study physicians had low levels of awareness of the content of the specific CCCD guidelines, most of their perceptions discussed here are about guidelines in general.

Perceptions ranged from regarding CPGs as providing optional guidance or advice that might inform clinical judgment and behaviour, to a more stringent set of "laws" or protocols that should determine judgment and behaviour. There is also evidence from our data that physicians tend to shift their positions on this issue depending on their level of familiarity with the substance of the CPGs, appreciation of the CPGs' effectiveness in practice, and assessment of the CPGs' relevance to individual patients, beginning with more rigid compliance and tending to become more selective in interpretation and application. One reason for this tendency might derive from the culture of family medicine itself, which might be preferred as a discipline by independently minded professionals who place high value on exercising their own clinical judgment in the context of "real" people in complex social, economic, and clinical circumstances. For such individuals "prescriptive" CPGs are more likely to be regarded as not helpful in practice.[15] Also related to this dichotomy is family physicians' appreciation of the nature of evidence encapsulated within CPGs, which they might or might not perceive as appropriate within those "real-life contexts," whether they are, in fact, or not.[16,17]

Relevance

Perceived irrelevance of the evidence is embodied within another of the themes to emerge from the data: a strong desire that guidelines be developed with much greater input from family physicians or from those familiar with their day-to-day work environments. Guidelines developed in this way are likely to have much greater credibility among family physicians. Langley et al also identified variations in practice environments, lack of time to assess guideline-related evidence, and no sense of ownership over guidelines among family physicians as barriers to their implementation in practice.[7] There is more than 20 years' worth of theoretical and empirical evidence regarding effective knowledge transfer.[18-20] Audiences are more likely to process and adopt behavioural messages if they believe (rightly or wrongly) that the messenger is not only knowledgeable about the subject, but also about the audience and its context, and about the effects and relevance of the message for both. Greater involvement of family physicians in guideline development and dissemination could potentially overcome these barriers.

The key to reconciling these issues is to ensure effective representation of the target audience in the guideline development and dissemination processes. Of the participants in the 1999 CCCD guidelines process, only 1 member of the 8-member steering committee was a family physician, and only 4 of the 32 participants were family physicians.[2] Little research has been done to examine the optimal composition of guideline committees and the role of family physician participants. In this study family physicians reported that they were underrepresented on guideline panels. Further research might be necessary to determine whether or not family physicians' greater involvement on guideline committees would result in better uptake of CPG recommendations.

Participants in our study also desired input from patients with dementia and family caregivers in future guideline development. Perceived lack of input from these stakeholders has previously been identified as a concern,[17] and reflects a perceived discrepancy similar to that described above. Here the discrepancy is between the imperatives inherent in the scientific environment of guideline development, and those inherent in the complicated, pragmatic environment of day-to-day life. Failure to reconcile this discrepancy once again results in guidelines being judged as irrelevant to existing circumstances.

Access

Family physicians in previous studies have strongly expressed that guidelines should be delivered in multiple formats, including flow sheets, algorithms, and outlines.[21] As previously described[7] our physicians also requested that guidelines be available in both paper and electronic forms, as summaries or "1-pagers," available for use with personal digital assistants. Accessibility appears to be key: given the variation in family practice environments, organizational structures, processes, and practice case-mixes, no single dissemination strategy is likely to appropriately target and effectively reach more than a minority of intended recipients. Multiple dissemination strategies increase the probability of effective communication and facilitate audience members in choosing their own "best method" of access.

Industry bias

Although other research has shown that physicians' attitudes to guidelines are influenced by hidden political and economic motives behind the evidence,[18] some family physicians in this study strongly expressed concerns about the role of the pharmaceutical industry in the development of the CCCD guidelines and guidelines in general. Conversely, the results of a previous survey showed that 87% of family physician respondents disagreed with the statement "I am less likely to trust guidelines if commercial companies have been involved."[19]

These concerns are justified by the fact that the CCCD guideline development was financially supported equally by 7 pharmaceutical companies.[2] Furthermore, the 1999 CCCD guidelines clearly recommended the use of donepezil for mild to moderate dementia, in spite of limited efficacy data.[2] This contributes to the perception that pharmaceutical companies influenced the recommendations for drug therapy.

Limitations

Group dynamics in focus groups might favour the articulation of dominant views while silencing dissenting opinions. It is difficult to assess whether this was a limitation in these focus groups, as there appeared to be strong consensus around several themes; however, all groups had at least one dominant speaker. Greater homogeneity within the focus groups might have focused the discussion on the CCCD guidelines rather than on a general discussion of guidelines. Our group was diverse (all were family physicians but with a range of experience caring for patients with dementia), but reflective of shared experiences when assessing, treating, and managing patients with dementia.

Conclusion

Family physicians in this study were minimally aware of the 1999 CCCD CPGs, resulting partly from an ineffective passive dissemination strategy. As in other studies, family physicians acknowledged the potential of future dementia CPGs to assist them in patient care and identified ways in which future guidelines could be more effectively developed and disseminated to improve their uptake.

Future guidelines should more accurately reflect the day-to-day practice experiences and challenges of family physicians in the provision of dementia care. Whether this is best achieved by encouraging greater participation from family physicians in guideline development or by other means is not clear and should be the focus of future research. Guideline developers should also be cognizant of family physicians' perception that pharmaceutical companies' funding of the CCCD guidelines undermines their objectivity and credibility.

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Contributors

Drs Pimlott and **Persaud** conceived and designed the study with substantial input from **Drs Drummond** and **Cohen. Drs Pimlott** and **Persaud** were involved in data collection. **Drs Drummond** and **Persaud** provided methodologic expertise and guidance on the analysis of the data. **Drs Pimlott** and **Persaud** analyzed the data with substantial input from **Drs Cohen, Hollingworth, Seigel, Dalziel,** and **Silvius. Dr Pimlott** drafted the manuscript. All of the authors had substantial input into the manuscript at various stages, and all authors gave approval of the final version of the manuscript submitted.

Competing interests

Dr Dalziel has participated in national and regional advisory boards and received honoraria for continuing medical education events and development of educational materials from the following companies associated with medications available for treatment of dementia: Janssen-Ortho, Lundbeck, Novartis, Pfizer, and Wyeth. None of the other authors has any competing interests.

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