COMMENTARY

Caring for seniors living with dementia means caring for their caregivers too

Annie Poirier, MSc,[1–3] Philippe Voyer, PhD,[1,2,4] France Légaré, MD, PhD,[1,3] Michèle Morin, MD,[2,5] Holly O. Witteman, PhD,[1,3] Edeltraut Kröger, PhD,[1,2,6] Bernard Martineau, MD, PhD,[7] Charo Rodríguez, MD, PhD,[8] Anik MC Giguere, PhD[1–3]

ABSTRACT

To improve the care of seniors living with dementia, current initiatives typically target better identification and treatment of the patient. Our recent survey, however, shows we should also focus more on the needs of the informal caregivers who care for this population in primary care settings. This three-round Delphi survey sought caregivers' views on the most frequent and difficult decisions that seniors with dementia, their informal caregivers, and health care providers face in primary care settings in the province of Quebec. Respondents consisted of 31 health care professionals, informal caregivers, managers, representatives of community-based organizations devoted to these seniors, and clinical researchers involved in the organization of care or services to seniors with dementia. When we asked respondents to rank 27 common but difficult decisions involving benefit/harm trade-offs, 83% ranked the decision to choose an option to reduce the burden of informal caregivers as one of the five most important decisions. Choosing a treatment to manage agitation, aggression or psychotic symptoms followed closely, with 79% of respondents selecting it as one of the five most important decisions. Our results point to the importance of attending to the needs of informal caregivers and improving the management of behavioural and psychological symptoms of dementia.

KEY WORDS: Caregivers; aged; dementia; spouse; decision making; decision support technique

La traduction du résumé se trouve à la fin de l'article.

Can J Public Health 2017;108(5-6):e639–e642
doi: 10.17269/CJPH.108.6217

In 2015, 47 million people worldwide were living with dementia, and this number is expected to reach 75 million by 2030.[1] The growing number of people affected, combined with the evolving nature of their symptoms, is placing an increasing economic burden on the health care system and causing major public health challenges.[2] Although more and more attention is being given to the early diagnosis and treatment of dementia, much of this focus remains on the patient.

The majority of people with dementia live in communities where family members and friends care for them.[3] As dementia progresses, people increasingly rely on informal caregivers for assistance with day-to-day activities, management of symptoms, and maintenance of a supportive environment that provides an optimal quality of life.[3] Informal caregivers are also essential to translate the values of the person living with dementia into decision-making.[4] Studies show that informal caregivers of people with dementia experience high levels of burden, distress, social isolation, physical ill health, and financial hardship.[5–8] Depression in the informal caregiver is associated with a reduction in the involvement of the person with dementia in decisions.[9]

Our health care systems thus fail to meet the informal caregivers' needs, despite their key role in supporting community-based people living with dementia. Informal caregiver needs are so important that they were prioritized over those of the patients during our survey of caregivers' views on the most frequent and difficult decisions of seniors living with dementia, their informal caregivers, and primary health care providers. Thirty-three people involved in the care of seniors living with dementia took part in this three-round online Delphi survey (78% response rate). The respondents consisted of health care professionals, informal caregivers, managers, representatives of community-based organizations devoted to these seniors, and clinical researchers involved in the organization of primary care or services delivered to seniors with dementia in the Province of Quebec (Table 1).

An introduction to the survey clarified that the findings would allow prioritizing five decisions, for which we would develop training material for patient, informal caregivers, and health care providers to support shared decision-making among them. The survey initially listed 24 common but difficult decisions involving benefit/harm trade-offs, which we identified through a review of the literature and on the basis of the clinical experience of some of the

Author Affiliations

1. Research Centre of the CHU of Quebec, Quebec City, QC
2. Quebec Excellence Centre on Aging, St. Sacrement Hospital, Quebec City, QC
3. Department of Family and Emergency Medicine, Laval University, Quebec City, QC
4. Faculty of Nursing, Laval University, Quebec City, QC
5. Department of Medicine, Laval University, Quebec City, QC
6. Faculty of Pharmacy, Laval University, Quebec City, QC
7. Department of Family and Emergency Medicine, Sherbrooke University, Sherbrooke, QC
8. Department of Family Medicine, McGill University, Montreal, QC

Correspondence: Anik MC Giguere, PhD, Department of Family and Emergency Medicine, Laval University, Pavillon Ferdinand-Vandry, Room 2881-C, 1050 avenue de la Médecine, Quebec City, QC G1V 0A6, Tel: 418-656-2131, ext. 8026, E-mail: anik.giguere@fmed.ulaval.ca

Acknowledgements: This work was supported by the Ministre de l'Économie, de l'Innovation et des Exportations du Québec, SOVAR, Laval University's Department of Family Medicine and Emergency Medicine, and by the Research Chair in Aging at Laval University. We wish to acknowledge the significant contribution made by the experts in this study, as well as the support provided by the *Collaboration and Patient Partnership Unit* of the University of Montreal in identifying informal caregiver representatives. We also wish to thank Selma Chipenda Dansoko and Katherine Hastings for their writing assistance.

Conflict of Interest: None to declare.

Table 1. Demographic characteristics of survey respondents

All respondent characteristics (*n* = 31; 2 missing)	**Number (%)**
Sex	24 (77%)
Female	
Age (years)	
<34s	3 (9%)
35–44	5 (16%)
45–54	10 (32%)
55–64	8 (26%)
≥65	5 (16%)
Type of respondent (non-mutually-exclusive categories)	
Informal caregiver	11 (35%)
Primary health care provider caring for seniors with dementia	24 (77%)
Clinical researcher involved in the organization of care or services to seniors with dementia	7 (23%)
Managers or representatives of community-based organizations devoted to these seniors	7 (23%)
Characteristics of primary health care providers (*n* = 24)	**Number (%)**
Profession	
Physician	9 (38%)
Nurse	7 (29%)
Social worker	2 (8%)
Occupational therapist	2 (8%)
Other (psychologist, specialized educator, neuropsychologist, quality improvement advisor)	4 (16%)
Years caring for seniors with dementia, mean (SD)	18.3 (10.8)
Years of practice, mean (SD)	25.5 (12.4)
Characteristics of managers and representatives of community-based organizations (*n* = 7)	**Number (%)**
Mission of the organization (non-mutually-exclusive categories)	
General care	3 (43%)
Education to medical and nursing students	3 (43%)
Patient care follow-up	3 (43%)
Caregiver services	2 (29%)
Evaluation and orientation	2 (14%)
Years delivering care to seniors with dementia, mean (SD)	19.3 (10.2)
Characteristics of the participating researchers (*n* = 7)	**Number (%)**
Field of research	
Palliative care	2 (29%)
Caregiver	2 (29%)
Promotion, prevention, and early diagnosis	2 (29%)
Aging	2 (28%)
Nursing	1 (14%)
Years studying senior care, mean (SD)	22.9 (10.2)

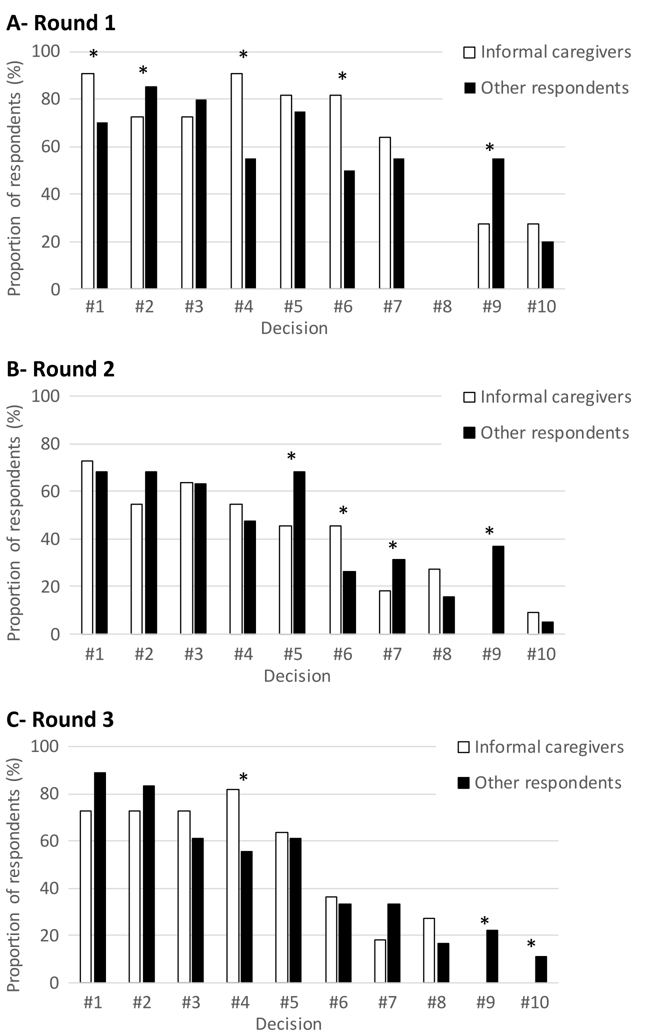

Figure 1. Rankings of the first 10 prioritized decisions by informal caregivers and other respondents (health care providers, researchers, managers or representatives of community-based organizations) during (A) round 1, (B) round 2, and (C) round 3. The asterisks indicate a statistically significant difference between informal caregivers and the other respondents (chi-square test followed by a Kruskal–Wallis post hoc test) (see Table 2 for a description of the decisions)

team members (MM, EK). In the first survey round, we asked the respondents to select up to 10 of the most important decisions for seniors living with dementia and their informal caregivers, and provided space to identify decisions that might have been missing from the initial list. From the results, we created a list of decisions that at least one respondent selected or suggested, and indicated the frequency with which each decision was selected. In the second round, we asked respondents to select the five most important from this list. In the third and final round, we again reported the frequency of responses from the previous round and asked respondents to select the five decisions they perceived as most important. We then calculated the frequency of respondents who selected each decision. The study was deemed exempt by the Central Research Ethics Committee of Quebec's Ministry of Health and Social Services.

Completion rates for each round of the Delphi survey were 94%, 91%, and 88% for rounds 1, 2, and 3 respectively. After the first round, we added three decisions proposed by participants, giving 27 decisions to choose from. Of these 27 decisions, in round 3, respondents most frequently selected 1) Choosing a support option to decrease the burden of informal caregivers of seniors with dementia, or to improve their quality of life (83%); 2) Choosing a treatment to manage agitation, aggression, or psychotic symptoms in seniors with dementia (79%); 3) Deciding whether or not to stop driving following a diagnosis of dementia (66%); 4) Establishing care goals for seniors with dementia (66%); and 5) Deciding whether or not to prepare advanced directives following a diagnosis of dementia (62%) (Table 2). The decision whether or not to relocate seniors (#6) was ranked sixth in the third round (34%). Decisions about pharmacological treatment (#7, #13, #22, #23) were not a high priority. Figure 1 allows comparison of

Table 2. Ranking of decisions by respondents in each of the Delphi rounds

	Decision to be made through shared decision-making among the patient, informal caregiver and health care provider	Round 1	Round 2	Round 3
1.	Choosing a support option to decrease the burden of informal caregivers of seniors with dementia, or to improve their quality of life	77%	71%	83%
2.	Choosing a treatment to manage agitation, aggression, or psychotic symptoms	81%	65%	79%
3.	Deciding whether or not to stop driving following a diagnosis of dementia	77%	65%	66%
4.	Establishing care goals for seniors with dementia (e.g., prolong life, maintain or improve quality of life, or provide comfort care)	68%	48%	66%
5.	Deciding whether or not to prepare advanced directives following a diagnosis of dementia	77%	58%	62%
6.	Deciding whether or not to adapt the home or relocate	61%	32%	34%
7.	Choosing medications to maintain cognitive function (e.g., aspirin, anti-inflammatories, cholinesterase inhibitors, memantine, statins)	58%	26%	28%
8.	Establishing a treatment plan based on an assessment of the needs of the senior and their caregivers*	N/A	19%	21%
9.	Choosing non-pharmacological interventions to reduce BPSD (e.g., cognitive approaches, sensory interventions, diet change, vocational training)	45%	23%	14%
10.	Deciding whether or not to partake in physical activity to maintain cognitive function	23%	6%	7%
11.	Deciding whether or not to maintain cognitive function through cognitive or behavioural interventions (e.g., dyadic interventions, cognitive stimulation, ergonomic therapy, validation therapy/empathy)	35%	13%	7%
12.	Deciding whom to tell about the diagnosis of dementia*	N/A	10%	7%
13.	Deciding which of the three cholinesterase inhibitors to try first, based on their risks and benefits	26%	3%	3%
14.	Deciding whether or not to reduce behavioural and psychological symptoms through social interaction	45%	10%	3%
15.	Choosing therapeutic options to reduce anxiety	35%	3%	3%
16.	Choosing therapeutic options to reduce sleep impairment	42%	3%	3%
17.	Asking for medical aid in dying to relieve suffering*	N/A	6%	3%
18.	Deciding whether or not to leave the senior with dementia alone	65%	16%	0%
19.	Choosing therapeutic options to reduce apathy	13%	6%	0%
20.	Maintaining cognitive function with food supplements (e.g., folic acid with or without vitamin B12, ginkgo biloba, vitamin B6, curcuma)	3%	0%	N/A
21.	Maintaining cognitive function through other non-pharmacological treatments (e.g., acupuncture, diet change, occupational therapy, aromatherapy, music)	23%	0%	N/A
22.	Choosing alternative treatments when a first cholinesterase inhibitor is unsuccessful or produces intolerable side effects	26%	0%	N/A
23.	Maintaining cognitive function using combination therapy (cholinesterase inhibitor and memantine)	19%	0%	N/A
24.	Reducing behavioural and psychological symptoms through physical activity	13%	0%	N/A
25.	Choosing therapeutic options to reduce depression	26%	0%	N/A
26.	Choosing therapeutic options to reduce appetite/eating impairments	13%	0%	N/A
27.	Choosing therapeutic options to reduce inappropriate sexual behaviour	16%	0%	N/A

* Decisions proposed by study participants.
Note: BPSD = behavioural and psychological symptoms of dementia.

rankings by informal caregivers with those of the other respondents. Notably, the decision to choose a support option to decrease the burden of informal caregivers of seniors with dementia (#1) was more frequently selected by informal caregivers in round 1, but not in rounds 2 or 3. We also note that question #2 was ranked more highly in the first round by the respondents who were not informal caregivers compared to those who were, and that question #9 was consistently ranked more highly in all of the three rounds by the respondents who were not caregivers compared with those who were.

CONCLUSION

To improve the care of seniors living with dementia, survey respondents deemed it a priority to provide information with which to address the decisional needs of informal caregivers to help them choose an option to reduce their burden. This points to the prominent role played by caregivers in the care of seniors living with dementia. Helping informal caregivers choose a support option to reduce their burden holds the potential of improving not only their own health but also the health of those they are helping,[10,11] while allowing them to live longer in their communities and thus reducing the utilization of health care resources.[12]

Informal caregivers are responsible for a wide range of care responsibilities. They serve as an intermediary between patients and the health care system by participating in the evaluation and management of behavioural symptoms and functional limitations. They also play a key role in securing medical, social, and financial support (including home care and guardianship); seeking temporary or permanent accommodation; and securing assistive technology.[13] Other studies have shown that clinicians and caregivers lack awareness of the available community resources.[14]

The survey respondents ranked question #2 closely to question #1, thus prioritizing the provision of information to address the decisional needs of patients and their caregivers to manage agitation, aggression and psychotic symptoms (question #2). These behavioural and psychological symptoms of dementia are also named “unmet need behaviours”,[15] and can be managed through person-centred care focusing on these needs.[15,16] Inclusion of informal caregivers into such care should improve person-centred care approaches that consider patients’ priorities and needs through shared decision-making[17] and in turn contribute to reducing behavioural and psychological symptoms of dementia, and avoiding institutionalization. In general, respondents seem to have focused more on decisions regarding psychosocial aspects of care and services as opposed to medical decisions, pointing to the importance of community-based resources to answer the more prominent needs of people living with dementia. They also seem to have ranked the more specific decisions (sexual behaviours, eating or sleep impairments, anxiety) lower, in favour of the decisions with broader scopes (behavioural and psychological symptoms of dementia, caregiver burden). The respondents also ranked the decisions relative to improving cognitive function lower, perhaps because of the limited efficacy of the current pharmacological treatments to stop or slow down cognitive decline.[18]

In the process of adjusting and coping, people living with dementia and their caregivers have a number of difficult but important decisions to make related to care, medication, safety, relocation and protection, and respite services. However, in order to make informed decisions, they need access to high-quality information and support to help examine and clarify their values about available options, a need that has consistently been identified as pressing but unmet.[19,20] There is therefore a clear demand for research to explore these decisional needs further, in order to design tools to address them and to support people with dementia and their caregivers in making informed and values-based decisions.

In conclusion, our results point to the importance of attending to the needs of caregivers, who are key players in providing care and making decisions with, or on behalf of, seniors with dementia. The caregiver's role in caring for seniors living with dementia needs to be better recognized and supported in the health care system and in our communities. Access by informal caregivers to support services should also be facilitated, for example, by better informing clinicians about the services available to them, in particular those offered by the Alzheimer's Society. Communication and coordination among all parties involved in caring for seniors with dementia, including informal caregivers, are also warranted.

REFERENCES

1. Prince M, Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina M. *World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost & Trends*. London, UK: Alzheimer's Disease International, 2015.
2. Dudgeon S. *Rising Tide: The Impact of Dementia on Canadian Society: A Study*. Toronto, ON: Alzheimer Society of Canada, 2010.
3. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *J Am Geriatr Soc* 2013;61(12):2087–95. PMID: 24479141. doi: 10.1111/jgs.12549.
4. Miller LM, Whitlatch CJ, Lyons KS. Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia (London)* 2016; 15(5):1141–57. PMID: 25370075. doi: 10.1177/1471301214555542.
5. McCurry SM, Logsdon RG, Teri L, Vitiello MV. Sleep disturbances in caregivers of persons with dementia: Contributing factors and treatment implications. *Sleep Med Rev* 2007;11(2):143–53. PMID: 17287134. doi: 10.1016/j.smrv.2006.09.002.
6. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *J Soc Work Educ* 2008;44(Suppl 3):105–13. doi: 10.5175/JSWE.2008.773247702.
7. Pinquart M, Sörensen S. Correlates of physical health of informal caregivers: A meta-analysis. *J Gerontol Ser B* 2007;62(2):P126–37. doi: 10.1093/geronb/62.2.P126.
8. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychol Aging* 2003;18(2):250–67. PMID: 12825775. doi: 10.1037/0882-7974.18.2.250.
9. Menne HL, Tucke SS, Whitlatch CJ, Feinberg LF. Decision-making involvement scale for individuals with dementia and family caregivers. *Am J Alzheimers Dis Other Demen* 2008;23(1):23–29. PMID: 18276955. doi: 10.1177/1533317507308312.
10. Morlett Paredes A, Perrin PB, Peralta SV, Stolfi ME, Morelli E, Arango-Lasprilla JC. Structural equation model linking dementia cognitive functioning, caregiver mental health, burden, and quality of informal care in Argentina. *Dementia (London)* 2015;16(6):766–79. PMID: 26589535. doi: 10.1177/1471301215617080.
11. Lethin C, Renom-Guiteras A, Zwakhalen S, Soto-Martin M, Saks K, Zabalegui A, et al. Psychological well-being over time among informal caregivers caring for persons with dementia living at home. *Aging Ment Health* 2016;21(11):1138–46. PMID: 27463390. doi: 10.1080/13607863.2016.1211621.
12. World Health Organization. *Dementia: A Public Health Priority*. Geneva, Switzerland: World Health Organization, 2012.
13. Amieva H, Rullier L, Bouisson J, Dartigues JF, Dubois O, Salamon R. [Needs and expectations of Alzheimer's disease family caregivers]. *Rev Epidemiol Sante Publique* 2012;60(3):231–38. PMID: 22595420. doi: 10.1016/j.respe.2011.12.136.
14. Jensen CJ, Inker J. Strengthening the dementia care triad: Identifying knowledge gaps and linking to resources. *Am J Alzheimers Dis Other Demen* 2015;30(3):268–75. PMID: 25118334. doi: 10.1177/1533317514545476.
15. Chenoweth L, King MT, Jeon YH, Brodaty H, Stein-Parbury J, Norman R, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *Lancet Neurol* 2009;8(4):317–25. PMID: 19282246. doi: 10.1016/S1474-4422(09)70045-6.
16. Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: Current status and ways forward. *Lancet Neurol* 2008;7(4):362–67. PMID: 18339351. doi: 10.1016/S1474-4422(08)70063-2.
17. Mariani E, Vernooij-Dassen M, Koopmans R, Engels Y, Chattat R. Shared decision-making in dementia care planning: Barriers and facilitators in two European countries. *Aging Ment Health* 2017;21(1):31–39. PMID: 27869501. doi: 10.1080/13607863.2016.1255715.
18. Blanco-Silvente L, Castells X, Saez M, Barceló MA, Garre-Olmo J, Vilalta-Franch J, et al. Discontinuation, efficacy, and safety of cholinesterase inhibitors for Alzheimer's disease: A meta-analysis and meta-regression of 43 randomized clinical trials enrolling 16 106 patients. *Int J Neuropsychopharmacol* 2017;20(7):519–28. PMID: 28201726. doi: 10.1093/ijnp/pyx012.
19. McCabe M, You E, Tatangelo G. Hearing their voice: A systematic review of dementia family caregivers' needs. *Gerontologist* 2016;56(5):e70–88. PMID: 27102056. doi: 10.1093/geront/gnw078.
20. van der Roest HG, Meiland FJ, Comijs HC, Derksen E, Jansen AP, van Hout HP, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatr* 2009; 21(5):949–65. PMID: 19602305. doi: 10.1017/S1041610209990147.

Received: April 4, 2017
Accepted: August 3, 2017

RÉSUMÉ

Les initiatives visant à améliorer les soins aux personnes âgées atteintes de démence ciblent généralement une meilleure identification et un meilleur traitement du patient. Notre sondage montre toutefois que nous devrions nous concentrer davantage sur les besoins des aidants naturels qui s'occupent de cette population en première ligne. Ce sondage Delphi en trois rondes a permis de recueillir les opinions des soignants sur les décisions les plus fréquentes et les plus difficiles auxquelles sont confrontés les aînés atteints de démence, leurs aidants naturels et les professionnels de la santé et des services sociaux œuvrant en première ligne au Québec. Les répondants comprenaient 31 professionnels de la santé et des services sociaux, des aidants naturels, des gestionnaires, des représentants d'organismes communautaires dédiés à ces aînés et des chercheurs-cliniciens impliqués dans l'organisation de soins ou de services aux personnes âgées atteintes de démence. Nous avons demandé aux répondants de classer 27 décisions fréquentes, et difficiles en raison des avantages et des inconvénients qu'elles comportent. La majorité (83 %) a priorisé la décision de choisir une option pour réduire le fardeau des aidants naturels parmi les cinq décisions les plus importantes. Le choix d'un traitement pour gérer l'agitation, l'agressivité ou les symptômes psychotiques a suivi de près, avec 79 % des répondants l'ayant choisi comme l'une des cinq décisions les plus importantes. Nos résultats soulignent l'importance de répondre aux besoins des aidants naturels et d'améliorer la gestion des symptômes comportementaux et psychologiques de la démence.

MOTS CLÉS : proches aidant; vieillissement; démence; troubles cognitifs; prise de décision; outils d'aide à la décision