

Development of a tool to investigate caregiving issues from the perspective of family physicians and discussion of preliminary results

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Aim: The aim of our study was to develop a survey for family physicians to better understand family physicians' beliefs, level of knowledge and sense of accountability regarding their support of informal (ie, unpaid) caregivers of older adults. **Background:** Seniors with dementia can be supported to 'age in place'. However, this requires assistance from family and friends, who are often seniors themselves and may have health issues of their own. Although family physicians are well positioned to assist older adult caregivers, there is a paucity of data regarding this role. **Methods:** After a literature review, we created a questionnaire to examine these issues. It was reviewed by experts and, after revision, was appraised by health planners/decision makers and pre-tested with family physicians. A final questionnaire was created using this feedback. **Findings:** The next important step would be to administer the questionnaire to Canadian family physicians using appropriate survey methodology.

Keywords: caregiver; family physician; survey

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Background

The population of adults 60 years and over continues to increase and by 2050 ~20% of the world population will fall in this age cohort (United Nations, 2002). Most of these older adults will develop health issues. For example chronic diseases, including hypertension, arthritis, and diabetes, affect a large percentage of older adults (Schoenborn and Heyman, 2009; Butler-Jones, 2010; Bielak *et al.*, 2012) and increasing numbers of older adults have Alzheimer disease and other

dementias (Prince *et al.*, 2013). Despite this governments in many countries acknowledge that seniors should be supported to 'age in place' (Colombo *et al.*, 2011). However, to achieve this goal, seniors with health issues will require assistance, mostly from family and friends, the so-called 'informal caregivers', many of whom are seniors themselves (Cranswick and Dosman, 2008; National Alliance for Caregiving and AARP, 2009). This has resulted in a shifting of the burden of care from the formal system to informal caregivers; and formal (ie, paid) caregivers now perceive informal caregivers as important contributors (Guberman *et al.*, 2006).

Caregiving places considerable burden on the health and well-being of caregivers; caregivers are

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at significantly higher risk for depression, anxiety, chronic illnesses, and stress-related conditions such as heart disease, hypertension, and sleep disorders (Pinquart and Sorensen, 2003; Vitaliano *et al.*, 2003; Schoenmakers *et al.*, 2010; Collins and Swartz, 2011). They take on responsibilities that are intense and many report this care provision is nonstop (Bédard *et al.*, 2005).

Research has identified the importance of the health care system in supporting caregivers (Bulsara and Fynn, 2006). However, in the traditional view, the caregiver, who is not a client, is identified as an informal support to the patient and is typically outside the realm of health professional responsibility. We argue that care recipient and caregiver form a dyad to be viewed as one entity; healthy caregivers are important resources for care recipients.

Family physicians (and other health professionals) are uniquely positioned to play a critical role in caregiving situations, including the assessment of caregivers' health (Silliman, 2000; Yaffe and Jacobs, 2008; Horgan *et al.*, 2009). They have been identified as critical in providing dementia education to caregivers, in addressing psychological issues experienced by these individuals, and helping them develop social support networks (Cohen *et al.*, 2001; Hogan *et al.*, 2007; Third Canadian Consensus Conference, 2007; Mitnick *et al.*, 2010; Collins and Swartz, 2011).

However, research has identified that this may not be how caregiver/family–physician relationship are actualized. Bulsara and Fynn (2006) found that although 96% of physician respondents believed they were able to assist with caregiver needs, this was accomplished largely through providing practical assistance (eg, referrals to services). The family physicians were unable or unwilling to provide emotional or psychological support to caregivers. Yaffe *et al.* (2008) reported that while physicians recognized that caregivers needed quicker access to home care services, they were largely unaware of resources oriented to the needs of caregivers within their communities. Additionally, physicians thought that support for most caregivers' needs should come from other services. Similarly, Yaffe and Klvana (2002) found that while 91% of physicians felt that it was their responsibility to respond to the non-medical needs of caregivers, they identified lack of time and lack of adequate

remuneration as barriers to treatment. These two issues have been acknowledged as working in tandem to limit care family physicians are able to provide (Aminzadeh *et al.*, 2012). There is also evidence that physicians lack knowledge and training about caregiver-related issues; medical school training about this is limited (Yaffe and Jacobs, 2008). This education deficit has been identified as one of the barriers to providing optimal care (Aminzadeh *et al.*, 2012).

Physicians have a responsibility to identify caregivers at risk and to help caregivers access resources within the community. Furthermore, the role of the family physician should extend to giving instrumental advice, to normalizing the caregivers' feeling of resentment, anger, frustration, and ambivalence, and to encouraging them to take care of themselves physically and psychologically (Brotman and Yaffe, 1994; Sewitch *et al.*, 2006; Third Canadian Consensus Conference, 2007). However, we have limited knowledge from the perspective of family physicians about caregiving issues. This limits our opportunities to effect change of benefit to caregivers. Accordingly, we sought to develop a tool to better understand physicians' own attitudes, beliefs, level of knowledge, perceived barriers, and sense of accountability regarding their support of caregivers.

Method

Questionnaire development and pre-testing

We searched for studies using databases such as PubMed and also consulted the grey literature (eg, policy reports). Search terms included: caregiver, physician, health, and relationship. The literature review yielded the following three domains:

- (1) health outcome and accountability (eg, caregivers' health, validation of role, case management, family physician as part of the solution to caregiver issues, provide emotional support to caregivers),
- (2) preparation (eg, training to identify caregivers and their needs, training to provide education to caregivers, knowledge about services for patients), and
- (3) perceived barriers (eg, time, reimbursement, understanding, time to address caregiver issues).

From these domains, Version I of the survey was created with 38 questions rated on a five-point

scale (strongly disagree to strongly agree). There were questions regarding: general caregiving issues, caregivers who are patients, and caregivers who are not patients. The survey ended with demographic questions modified from the National Physician Survey 2007 created by The College of Family Physicians of Canada, the Canadian Medical Association and The Royal College of Physicians and Surgeons of Canada.

Ethics approval for the study was obtained before pre-testing. The purpose of the pre-testing phase was to review and revise the questionnaire before distribution to participants (Burns *et al.*, 2008) to ensure respondents understand what is being asked (Collins, 2003). The questionnaire was first reviewed by a family physician and a geriatrician. As suggested by Campanelli (2008), panelists were provided with information about the study as well as the survey. Written feedback was received and appropriate revisions were made to create Version II of the survey.

The next component of the pre-testing phase consisted of semi-structured interviews with health planners/decision makers to review Version II of the questionnaire. A representative with the Ontario Ministry of Health and Long-Term Care and one from the Public Health Agency of Canada provided the researchers with a list of experts in health planning who had expressed interest in the project. The survey tool and cover letter were e-mailed to each participant before the interview. The telephone interviews were conducted by the primary investigator and research coordinator.

For the last component of the pre-testing phase, six family physicians from urban practices located in Thunder Bay, Ontario, Canada, and three family physicians from smaller communities in the surrounding region were interviewed over the telephone. Physicians were recruited initially from a list provided by the family physician who first reviewed the survey. Others were contacted at random in our community and in ten small communities nearby. Potential participants were faxed a letter informing them about the study, followed-up with a telephone call to formally solicit participation. Copies of the questionnaire were sent ahead of time. The interviews lasted ~1 h and were conducted by the primary investigator and the research coordinator. Physicians were compensated \$200.

During the interviews, attention was paid to mental processes used to answer the questions

using a combination of both think-aloud and probing techniques (Collins, 2003; Campanelli, 2008). For the think-aloud analyses, participants read aloud each question to share their thoughts as they decided upon their responses. Interviewers also used a series of pre-prepared probes (ie, questions developed before the interview) and spontaneous probes (ie, questions that the interviewer created during the interview to encourage further sharing). Responses from recorded and descriptive statistics were used to summarize this information. Upon completion of the interviews and review of the data the questionnaire was revised a final time.

Results

Feedback from expert panel

Written feedback from the expert panelists on Version I was mostly about formatting (eg, shortening, making it into a booklet). It was also suggested that the amount of time to complete the questionnaire be included. Appropriate revisions were made to create a second version of the survey.

Interviews with health planners/decision makers

Health planners/decision makers' comments can be divided into four broad categories: wording/language issues, questions to change or delete, questions to add, and general comments. Wording/language issues focused on clarifying questions and encouraged the use of positive language. Repetitive questions were eliminated and a question about medical school training regarding caregiving issues was added. General comments included the need to shorten the survey. While the focus of the survey was on caregivers providing support to individuals with dementia, respondents indicated that it could be modified to generic survey about all caregivers. They felt this type of survey would be very useful from a health planning perspective.

Interviews with family physicians

Nine family physicians completed interviews. Further demographic details can be found in Table 1. Similar to the health planners/decision makers, family physicians focused on four main

Table 1 Demographic details for family physician participants ($n = 9$)

Age [Mean (SD)]	44.4 (11.1)
Gender (female) [n (%)]	5 (55.6)
Number of years working in professional field [Mean (SD)]	15.7 (13.4)
Current work setting (more than one response possible) [n (%)]	
Private office/clinic	7 (77.8)
Nursing home/home for the aged	2 (22.2)
Community clinic/health centre	2 (22.2)
Community hospital	5 (55.6)
University/faculty of medicine	3 (33.3)
Free-standing walk-in clinic	1 (11.1)
Emergency department	2 (22.2)
Number of patients in practice [n (%)]	
<750	1 (11.1)
751–1500	2 (22.2)
1501–2250	1 (11.1)
2251–3000	2 (22.2)
>3001	1 (11.1)
Does not apply	2 (22.2)
Payment plan [n (%)]	
Fee for service	3 (33.3)
Capitation	2 (22.2)
Salary	3 (33.3)
Other	1 (11.1)

categories. Clarification/rewording was requested for some questions and redundant questions were identified. Suggested additions included providing space for written comments and the need for a question related to training received in medical school. Overall, physicians indicated that this survey was comprehensive and reflected their interactions with caregivers. They agreed the tool could be made generic to capture all caregivers. They felt it would be helpful to include a definition of ‘caregiver’.

The respondents’ scores for each question on the survey tool are presented in Table 2. To more fully examine the experiences of family physicians and caregivers, we analyzed questions that were identical but focused on caregivers who were patients versus those who were not, using independent samples *t*-tests. We also examined effect size using Cohen’s *d* (see Table 3). The results indicated that physicians felt greater responsibility for caregivers who are their patients compared with caregivers who are not their patients in some domains but not others. Most physicians reported they do not have enough time to interact with caregivers and some that they are not adequately reimbursed for supporting caregivers.

Final revisions

The questionnaire was revised to apply to all caregivers, five questions were split into two questions, five questions were removed, six questions were re-worded and two questions were added. The final questionnaire is available from the first author.

Discussion

We sought to develop a tool to assess family physician knowledge about caregiver issues and their views on their interactions with caregivers. Our approach entailed obtaining expert opinion as well as interviews with health planners/decision makers and family physicians to re-fine our survey tool. Overall, participants indicated that the data collected would be useful from a health planning perspective. During the interviews it was often suggested that the survey tool should be generic instead of focusing only on caregivers of seniors with dementia. This underscores the fact that informal caregivers, regardless of their situation, face common challenges and may experience strain. It was also suggested that the questions could be used to survey other healthcare professionals.

Further validation for the tool is evident when comparing questions for caregivers who are patients and those who are not. For most items family physicians ‘agreed’ or ‘strongly agreed’ when the caregiver was a patient but were neutral or ‘disagreed’ when the caregiver was not a patient. For example, physicians agreed/strongly agreed that they should respond to the medical needs of caregivers who were patients but disagreed/strongly disagreed when the caregiver was not a patient. A similar response pattern was evident for recommending/coordinating social services, advocating and providing support. It could be that they feel these issues should be addressed by caregivers’ own family physicians. However, physicians were open to providing education and instruction to all caregivers regardless of whether they are patients or not; there was no difference in questions related to telling caregivers about specialized services or community resources, educating them about their own health or the health of the care recipients. Physicians also more or less ‘agreed’ that they have a responsibility to identify burdened caregivers. Some physicians identified feeling inadequately

Table 2 Question responses (1 = strongly disagree to 5 = strongly agree)

		Mean	SD
General questions			
1.	I have sufficient knowledge to respond to the emotional/psychological needs of caregivers	3.56	0.53
2.	I understand the role of caregivers can be difficult	4.67	0.50
3.	I have sufficient knowledge to identify caregivers who may need assistance	3.33	1.00
4.	A healthy caregiver is the best source of support for a dementia patient	4.44	0.73
5.	I have sufficient knowledge to assess caregiver strain/burden	3.11	1.27
6.	There are adequate specialized services for caregivers in my community	2.22	0.83
7.	When it comes to caregiving issues, I am part of the solution	3.63	0.52
8.	I feel comfortable talking to caregivers in the presence of the dementia patients	3.89	0.33
9.	I feel comfortable talking to dementia patients in the presence of caregivers	4.22	0.44
10.	I have sufficient knowledge to educate caregivers about		
	(a) The patient's health	4.44	0.53
	(b) Specialized health services for patients	4.44	0.78
	(c) Potential impact on caregiver's health	3.56	0.88
	(d) Community resources for patients and caregivers	3.44	0.73
11.	I have sufficient knowledge to respond to the medical needs of caregivers	4.44	0.73
12.	The dementia patient's health outcomes are closely linked to the caregiver's health	3.89	1.05
13.	I have sufficient knowledge to assess the specific needs of caregivers	3.56	0.88
14.	Dementia patients and caregivers have different agendas (eg, staying home versus institutionalization)	4.11	0.78
Caregivers who are patients			
15.	It is my responsibility to identify caregivers who are strained	4.22	0.44
16.	It is my responsibility to recommend and coordinate social services for caregivers	4.00	0.50
17.	I have adequate time to take care of caregiver issues	2.44	1.24
18.	I must prioritize the dementia patient's medical issues first	3.56	1.13
19.	I am reimbursed adequately for supporting caregivers	3.00	1.23
20.	It is my responsibility to provide education to caregivers about		
	(a) The demented patient's health	4.56	0.53
	(b) Specialized health services for demented patients	4.33	0.50
	(c) Potential impact on caregiver's health	4.11	0.60
	(d) Community resources for patients and caregivers	4.33	0.50
21.	It is my responsibility to respond to the medical concerns of caregivers	4.56	0.53
22.	It is my responsibility to provide emotional support to caregivers	4.56	0.53
23.	It is my responsibility to provide assistance to caregivers experiencing emotional and psychological distress	4.44	0.53
24.	It is my responsibility to advocate on behalf of caregivers for access to services	4.11	0.93
25.	I should wait for caregivers to express strain/burden before discussing it with them	1.89	0.93
Caregivers who are not patients			
26.	It is more challenging to support caregivers who have a different family physician	4.22	0.67
27.	I feel comfortable taking care of caregivers even when they are not my patients	2.56	0.88
28.	It is my responsibility to identify caregivers who are strained	3.78	0.67
29.	It is my responsibility to recommend and coordinate social services for caregivers	2.89	0.60
30.	It is my responsibility to provide education to caregivers about		
	(a) The demented patient's health	4.44	0.53
	(b) Specialized health services for demented patients	4.33	0.50
	(c) Potential impact on caregiver's health	4.11	0.60
	(d) Community resources for patients and caregivers	4.11	0.60
31.	I have adequate time to take care of caregiver issues	2.00	1.00
32.	It is my responsibility to advocate on behalf of caregivers for access to services	2.89	1.17
33.	It is my responsibility to provide emotional support to caregivers	3.11	1.17
34.	It is my responsibility to provide assistance to caregivers experiencing emotional and psychological distress	2.33	0.71
35.	It is my responsibility to respond to the practical concerns of caregivers	3.63	0.52
36.	It is my responsibility to respond to the medical concerns of caregivers	1.88	0.99
37.	I am reimbursed adequately for supporting caregivers	2.33	1.12
38.	I should wait for caregivers to express strain/burden before discussing it with them	2.44	0.53

Table 3 Comparison of when the caregiver is a patient and when the caregiver is not a patient

Question	Patient		Not patient		t	p	d
	Mean	SD	Mean	SD			
Responsibility to identify caregivers who are strained	4.22	0.44	3.78	0.67	1.84	0.104	0.78
Responsibility to recommend and coordinate social services	4.00	0.50	2.89	0.60	5.55	0.001	2.01
Educate about patient's health	4.56	0.53	4.44	0.53	1.00	0.337	0.23
Educate about specialized services	4.33	0.50	4.33	0.50	0.00	1.00	0.00
Educate about impact on caregiver's health	4.11	0.60	4.11	0.60	0.00	1.00	0.00
Educate about community resources	4.33	0.50	4.11	0.60	1.51	0.169	0.40
Adequate time for caregiver issues	2.44	1.24	2.00	1.00	1.00	0.347	0.39
Responsibility to advocate on behalf of caregivers	4.11	0.93	2.89	1.17	5.50	0.001	1.15
Responsibility to provide emotional support	4.56	0.53	3.11	1.17	3.04	0.016	1.60
Responsibly to support caregivers experiencing stress	4.44	0.53	2.33	0.71	6.83	<0.001	3.37
Responsibility to respond to medical concerns of caregivers	4.50	0.54	1.88	0.99	6.25	<0.001	3.29
Reimbursed adequately for supporting caregivers	3.00	1.23	2.33	1.12	1.79	0.111	0.57
Wait for caregivers to express strain before discussing	1.89	0.93	2.44	0.53	1.89	0.095	0.73

remunerated for the care they provide and that they lack the time to address issues faced by all caregivers. This is likely a reflection of the current structure of health care delivery.

Conclusion

This pre-testing phase helped refine the survey tool to ensure it is appropriate and maximizes the usefulness of data generated. The next step is to administer the survey to a larger group of family physicians using appropriate survey methodology. These data would (1) allow further documentation of the psychometric properties of the tool (eg, factor structure, internal reliability), (2) provide actual data about the situation of family physicians, and (3) gauge the actual usefulness of the data for health planners and decision makers. A deeper understanding of physicians' attitudes, beliefs, level of knowledge, perceived barriers, and sense of accountability regarding their support of caregivers would help develop targeted interventions and training ultimately improving caregivers and care recipients' health outcomes.

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Conflict of Interest

None.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional guidelines on human experimentation (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans) and with the Helsinki Declaration of 1975, as revised in 2008.

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