

Role Expectations in Dementia Care Among Family Physicians and Specialists



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ABSTRACT

Background

The assessment and ongoing management of dementia falls largely on family physicians. This pilot study explored perceived roles and attitudes towards the provision of dementia care from the perspectives of family physicians and specialists.

Methods

Semi-structured, one-to-one interviews were conducted with six family physicians and six specialists (three geriatric psychiatrists, two geriatricians, and one neurologist) from University of Toronto-affiliated hospitals. Transcripts were subjected to thematic content analysis.

Results

Physicians' clinical experience averaged 16 years. Both physician groups acknowledged that family physicians are more confident in diagnosing/treating uncomplicated dementia than a decade ago. They agreed on care management issues that warranted specialist involvement. Driving competency was contentious, and specialists willingly played the "bad cop" to resolve disputes and preserve long-standing therapeutic relationships. While patient/caregiver education and support were deemed essential, most physicians commented that community resources were fragmented and difficult to access. Improving collaboration and communication between physician groups, and clarifying the roles of other multi-disciplinary team members in dementia care were also discussed.

Conclusions

Future research could further explore physicians' and other multi-disciplinary members' perceived roles and responsibilities in dementia care, given that different health-care system-wide dementia care strategies and initiatives are being developed and implemented across Ontario.

Key words: dementia, physicians, diagnosis, management, attitudes

INTRODUCTION

Dementia is a complex, progressive neurodegenerative disease that is difficult for both health-care professionals and family caregivers to manage. Currently, 500,000 Canadians have Alzheimer's disease and other dementias (ADOD). In one generation, this number will increase to 1.1 million.⁽¹⁾

There is broad consensus that the early detection of ADOD benefits both the person with dementia and their caregivers. Benefits include earlier access to treatment with cholinesterase inhibitors to delay the progression of symptoms of ADOD, earlier access to identify and treat associated symptoms, earlier referral for patient and family education and support (i.e., Alzheimer's Society chapters), access to psychosocial supportive services, and future planning.⁽²⁾ Currently there are not enough specialists to evaluate and care for the rising number of people with dementia and their informal caregivers.⁽³⁾ Therefore, family physicians are expected to play a central role in the diagnosis and management of uncomplicated dementia, and to act as case managers for people with dementia and their caregivers.⁽⁴⁾ While physicians' roles are alluded to in two Canadian practice guidelines,^(5,6) compliance is often poor,⁽⁷⁾ and there is little research examining

the expectations that family physicians and specialists have of themselves and of each other in dementia care. Lack of concordance between different physician groups may lead to suboptimal clinical care and work dissatisfaction.⁽⁸⁾ The purpose of this study was to explore perceived roles and attitudes toward the provision of dementia care from the perspective of family physicians and specialists, in the hope of improving health and social care services for patients and informal caregivers alike.

METHODS

Recruitment

Family physicians and specialists (a neurologist, geriatricians, and geriatric psychiatrists) were recruited from two University of Toronto academic health sciences centres and two community academic hospitals, according to a purposive quota sampling method which facilitated the inclusion of a range of relevant physician experiences and perspectives, including males and females, recent graduates, and more experienced practitioners in elder care.

Data Collection

Semi-structured, one-to-one interviews were conducted between July 2009 and August 2011 with six specialists and six family physicians. Interviews lasted between 20 and 60 minutes. Physicians received a \$100 honorarium for partial reimbursement for lost clinical time. Research Ethics Board approval was obtained from the University of Toronto, Women's College Hospital, North York General Hospital, and Sunnybrook Health Sciences Centre in Toronto, Ontario.

Interview Guide

The interview guide was developed, piloted, and subsequently revised to reflect emerging themes. The first part surveyed clinicians' characteristics and practice settings, and the second half consisted of open-ended questions to explore the expectations that family physicians and specialists had of themselves and of each other in five areas of dementia care: assessment and diagnosis; management (long-term and acute or "crisis" situations); medication therapy; and patient and caregiver education and support.

Data Analysis

Interviews were digitally audio-recorded and transcribed verbatim. To ensure confidentiality during transcription, names were omitted and individuals were assigned a study number. All transcripts were edited by the interviewer to ensure their accuracy. Transcripts were analyzed using a thematic content analysis approach. Three of the authors

read and re-read, and thematically coded the transcripts independently, then collectively either through face-to-face or telephone meetings. Coding was reviewed, and findings and emerging themes were discussed to ensure that they were grounded in the transcripts. Repeated reading of all the transcripts during the coding process ensured there were validity, depth, and breadth within each theme. Validation and consensus on themes was reached by referring back to the original transcripts, as often as required.

RESULTS

Sample Characteristics

The specialists comprised one female and two male geriatric psychiatrists, one male and one female geriatrician, and one female neurologist. Four of six family physicians were female. Specialists' and family physicians' clinical experience averaged 17.5 and 14.5 years, respectively (median 15.5 years for both groups).

Analysis of the transcripts identified six convergent themes:

1. Greater confidence in the diagnosis and initial management of dementia by family physicians compared to a decade ago.

There was mutual agreement between the two physician groups that straightforward cases of Alzheimer's disease should be diagnosed by family physicians.

"I think it should be within the realm of the family doctor." (FP#2)

"I think that family doctors should be able to make the diagnosis of dementia in most cases...and in an ideal world, they would." (SP#3)

Most physicians believed that family physicians, especially recent graduates, have enough training to diagnose dementia.

"I would say probably the younger ones are better. Are more in-tune, more aware of dementia and management and more comfortable, maybe, in diagnosing it, and discussing the diagnosis and providing support." (SP#1)

One specialist noted that older family physicians, who did not receive dementia training during residency, now have access to a myriad of Continuing Medical Education learning activities and dementia conferences. An older family physician noted that clinical experience and confidence in diagnosing dementia grew when she started seeing more people with dementia in her practice.

“Now I’m moving more and more towards, ‘Okay I can, I can diagnose this, and I can treat this;’ starting to feel more comfortable.” (FP#1)

Specialists also believed that family physicians should be capable of initiating, and monitoring response to cholinesterase inhibitors; and they, the specialists, should be consulted when there are medication complications. Both groups acknowledged that family physicians are more comfortable in the initial management of Alzheimer’s disease, compared to ten years ago, especially those who are younger or have more elderly patients in their practices.

“I definitely see family physicians getting more comfortable. There’s no question about it. I mean, they’re starting acetyl cholinesterase inhibitors and memory enhancers much more quickly; they’re much more comfortable than before. I think some of the younger ones are maybe a lot more comfortable.” (SP#4)

2. Management issues that warrant specialist involvement.

There was mutual agreement that the management of behavioural and psychiatric symptoms of dementia (BPSD) warrants referral to specialists; and most of the family physicians acknowledged that this aspect of dementia care is difficult and challenging. Many stated they are not comfortable prescribing psychotropics, especially because of Health Canada’s warnings (risk of strokes, even death). Therefore, most family physicians referred patients to a specialist (usually in a hospital-based geriatric program).

“I actually think that when they start exhibiting behavioural issues, I think that’s a good time to seek help for a family doctor because I think that there’s a lot of nuances to that and the medications that we use are not particularly safe. So I think that there is; I think that’s a good reason to seek expert advice when there’s behavioural issues, unless they’re very comfortable doing it themselves.” (SP#3)

“And it’s actually a lot easier for us to handle this earlier in the behavioural disturbance than when it’s become a real flagrant problem. And as you know, the treatment isn’t just drugs; a lot of it is counselling the family in terms of how to use some cognitive behavioural therapy to temper it down, and it’s really hard once everybody’s gotten into a routine of ‘You do this, I react, you get more upset, I get more reactive and now everybody’s in trouble and nobody wants to live in this house.’” (SP#5)

Both physician groups also agreed that the diagnosis of atypical dementias, management of complex, co-morbid

conditions involving polypharmacy, or a patient or a family caregiver’s request, especially for a second opinion, were also appropriate reasons for a specialist consultation. For example:

“If there is a patient preference for referral, they get referred, and if there are other management issues or the diagnosis is in doubt. Is it frontal lobe dementia? Is it Alzheimer’s or is it major behavioural issues?” (FP#4)

“I would like to see those cases that are not as straightforward or those cases where the family requests a second opinion from a specialist, or those cases where the family doctor feels that it, the management, will be complicated. Sometimes, the diagnosis itself is pretty straightforward, but because of a patient’s other health history, they can’t take the usual things that are prescribed, and then it is definitely reasonable to ask for a little help with that.” (SP#5)

3. “Good vs. bad cop” related to driving assessment/reporting.

Driving competency was identified as a difficult issue.

“It’s a big, ugly problem.” (SP#2)

“Families and patients get mad when driving is taken away.” (SP#1)

“It’s a dicey issue. It’s an important issue, the driving testing programs are expensive, and patients are not willing to do it.” (FP#2)

While most physicians agreed that it is their responsibility to report unsafe drivers to the Ministry of Transportation (MOT), most family physicians felt uncomfortable doing it.

“It’s the physician’s responsibility to notify the Ministry and advise the patient to stop driving if they’re not safe, so that could be either the specialist or the family doctor.” (SP#1)

“I hate that it has anything to do with my job. It should not be me (to report) because it can completely destroy the therapeutic relationship with the patient.” (FP#6)

Specialists understand that reporting to the Ministry may damage the patient–family physician relationship (e.g., the sense of trust the former has for the latter) and that many people have co-morbid conditions that require medical attention. Therefore, specialists reported willingly playing the “bad cop” role. As one summed up:

“I’ve definitely gone to consults regarding that [driving safety], and I don’t mind helping the family physician. I think it’s always better that I’m the bad guy than the family physician be the bad guy. If they don’t come back to see me, no problem; but they’ve got to at least maintain contact with the family physician.” (SP#4)

“I think a lot of the specialists understand that it’s such a tricky thing and I don’t think they enjoy doing it either, but I think they can appreciate that, that it’s important that the family doctor try to maintain a therapeutic relationship.” (FP#6)

4. Community supports are confusing and difficult to access.

Over two-thirds of the family physicians in this study recognized that counselling, educating and linking patients and their caregivers to community support services was a crucial role, and one that was expected of them.

“I think so. I mean they [family] definitely turn to you and I think to not have some steps that you take after that to try to get someone support would be not acceptable.” (FP#6)

“Yes, absolutely, either through CCAC (Community Care Access Centre: provides care coordination for community, social and home care services), or with a referral to our social worker here (Family Health Team), or through the Alzheimer’s Society, so I provide them with that information.” (SP3#)

Hospital-based specialists tended to be more knowledgeable about available community services. Physicians who were not familiar with such services did not have the time nor interest to make more inquiries about them. While only one specialist thought there were too many available resources, both physician groups agreed that programs and services were difficult to access.

“If nothing else, to educate and direct them in what’s available. And again, I’m not as well-versed on that as I should be so, but I certainly encourage them to network and get as much information as they can on their own, because they’re much more motivated than I am.” (FP#2)

“It’s overwhelming how much resources there are. But it’s kind of, all here, it’s over there, so that I think the family doctor should assist. But I even sometimes get lost about all the different programs there are out there. I can’t keep up, you know?” (SP#4)

More physicians referred to the CCAC than to the Alzheimer’s Society because *“family caregivers seem to prefer help from the CCAC, because services are provided at home, while Alzheimer’s Society services are off-site.” (FP#6)*

However, physicians from both groups sometimes felt their credibility was compromised when home-care services were suboptimal.

“The services that we refer them to, it just seems like there’s a real hit and miss... So it’s hard; you feel responsible because you made the referral, and I think it sort of damages your credibility, as well.” (SP#6)

To offset the confusion around fragmented resources, and access/referral to community and social support services for people with dementia and their family caregivers, physicians recommended that a coordinated, integrated telephone intake system or a frequently updated resources/services hand-out would be helpful. They suggested that enhanced collaboration between physicians and voluntary sector organizations, such as the Alzheimer’s Society, could also be improved.

“There should be some kind of a book that I can use; and it should be published every year and I can use that.” (FP#3)

“Yeah, some specialized intake. But there should be one input, where you write “consult” and then they look after everything, including the CCAC referrals. You know, like home OT safety assessments, a nurse, or personal support workers, as well as the Alzheimer’s Society and day programs.” (SP#4)

5. Physicians’ interactions and communication with each other were dependent on individual specialists and practice settings.

Family physicians in this study worked either in small group practices or in larger, multi-disciplinary family health teams. The interactions between family physicians and specialists were dependent upon the individual physicians.

“I think it really depends on the specialist. We have a lot of specialists who involve us and let us know about things and medications and this and that. And then there are other specialists who pretty much just manage that [diagnosis and management] and we have no interactions. It depends, it’s specialist-dependent.” (FP#6)

“So either the model is that you make suggestions and the family doctor decides what to implement. Or

you implement them and you share that information with the family doctor, one or the other, either is both fine.” (SP#3)

Some family physicians had a preference to whom they referred:

“Usually it’s the geriatrician that I work with, and I find that relationship very satisfying” (FP#4).

Others referred patients to hospital-based geriatric programs:

“I refer generally to the geriatric services, and I put in my concerns and I say, Well, this patient might have dementia or they might have a depression too, or they might have this and that and that. And then their intake nurse does a triage, and decides what they want to do with them.” (FP#3)

Regardless of which specialist was consulted, communication was generally one-way.

“Some [family physicians] are quite good at providing quite a bit of information, others don’t give more than one line to say dementia...So I guess that’s something that maybe needs to be worked on; is how to have better communication back and forth and so that both sides are happy.” (SP#1)

“Well it’s one-way. So the geriatrician will send me notes, not linked electronically. There’s no way for us to share the chart, which we’re going to be rectifying.” (FP#4)

“I ‘cc’ the family doctor on all of our notes. Interestingly, I don’t get any notes from the family doctors, except for the initial referral. I don’t get that many notes from family doctors. Many of those notes are just little quick—‘had a cough, gave antibiotics.’ So I don’t necessarily need those.” (SP#5)

6. Importance of shared and collaborative care to optimize delivery of dementia care.

Some physicians alluded to shared care models to improve dementia care.

“Yeah, so some sort of shared care with a dementia expert would be very helpful, if they would come and see the patients and work with you.” (FP#6)

“Of course, we should go to a shared care model. I don’t think that dementia care should belong in the hands of any individual specialist, or any particular group. It has to be a whole team approach. And I

also think that dementia care shouldn’t be just about dementia. These people often have other issues as well, so it needs to be like the whole person. It’s more about frail seniors than one specific disease. And it needs to be inter-professional, and it needs to cross the continuum of sectors and services.” (SP#6)

Other strategies mentioned to improve dementia care included a standardized assessment flowchart that family physicians can follow to expedite the diagnostic process (e.g., screening tools, past medical and psychiatric history, blood work, computerized tomography, if appropriate).

Once a diagnosis has been made, one specialist described, “putting together a year’s worth of algorithm.”

“This is the kind of medication I would start with, or at least use something from this class of drug, in case of this symptom getting worse, then do that. And so I’ve set up a roadmap that the family doctor can then follow.” (SP#5)

Another specialist described, “Once I’ve got them on a maintenance dose, then the family physician takes over.” (SP#4)

In terms of patient and caregiver education and support, physicians in both groups believed that non-physician members of a multi-disciplinary team could effectively carry out this crucial role.

“That a lot of the support that the caregivers need doesn’t need to be delivered by a physician, if they had access to nurses or social workers to help provide some of that.” (SP#3)

“But that’s where the multi-disciplinary thing is great, when you have then a social worker or a nurse who can then spend that other additional time.” (FP#6)

DISCUSSION

In this qualitative study, unlike earlier survey-based studies,⁽⁹⁻¹¹⁾ we elicited additional insight into family physicians’ and specialists’ expectations and attitudes toward several domains of dementia care. Both family physicians and specialists in this study acknowledged that the former group is now more confident in diagnosing and initiating/monitoring treatment with cholinesterase inhibitors for common forms of dementia than a decade ago.⁽¹⁰⁾ This trend towards greater confidence in the diagnostic process and initial management of dementia is due in part to the proliferation of dementia consensus position papers, clinical practice guidelines,^(5,6) and a myriad of CME initiatives and conferences in the last ten years.⁽¹²⁾ Furthermore, recent graduates received dementia care education during

their medical and residency training,⁽¹²⁾ while older physicians gained more clinical experience and confidence when they started seeing more patients with dementia in their practices. However, it remains to be seen whether this perceived trend translates into higher and earlier diagnostic rates, because under-recognition and delayed diagnosis of early stage dementia is widely documented in the current literature.⁽¹²⁾

Dementia care management issues that warrant referral to specialists are outlined in the 3rd CCCDTD⁽⁶⁾ recommendations, and family physicians in this study were aware of and concurred that the diagnosis of atypical dementias, unresponsiveness to dementia medications, management of complicated co-morbid conditions, and polypharmacy, and complying with patients' and/or family caregivers' requests (often for a second opinion) necessitated specialist involvement. Specialists also concurred with the CCCDTD guidelines that genetic counselling and enrollment into therapeutic clinical trials were also appropriate reasons for referral.^(5,6)

One area of dementia care that diverged from clinical practice guidelines was the medical management of behavioural and psychiatric symptoms of dementia (BPSD). As previously described in the literature, our physicians all acknowledged that BPSD is one of the most challenging aspects of dementia care, and warranted referral to a specialist.^(13,14) While many physicians felt uncomfortable prescribing antipsychotic medications due to Health Canada's warnings of increased risk of strokes, even death, to older adults with dementia, there appeared to be more referrals to specialists and more reliance on pharmacologic management, even before all non-pharmacologic approaches have been tried. As reported in one British chart audit study,⁽¹⁴⁾ and echoed by some of our specialists, family physicians should coach or refer informal caregivers to community agencies, such as the Alzheimer's Society chapters, for training in non-pharmacologic strategies such as interpreting meanings behind disruptive behaviours, using cognitive behavioural therapy, modifying the environment, and using gentle persuasive techniques to communicate with a person with dementia.⁽¹⁵⁾

Another difficult issue faced by family physicians caring for patients with mild cognitive impairment (MCI) or mild dementia is addressing driving competency, in particular, reporting unsafe drivers to licensing authorities.⁽¹⁶⁾ Despite practice guidelines urging family physicians to provide support and assistance with driving decisions,^(5,6) and acknowledging their legal responsibility to report unsafe drivers, most of our family physicians disliked this emotionally-charged task, and some even adamantly declared that driving cessation should be the responsibility of an independent physician-consultant within the Ministry of Transportation, or a hospital-based geriatric program. While some family physicians worried that patients and/or caregivers might become defensive or angry, others worried about the negative impact of license suspension on patients' self-identity, independence, and quality of life and, most importantly, that it could jeopardize, oftentimes long-standing, patient-physician relationships. Family physicians worried that patients

who "fired" them might forego ongoing medical care for other competing, complex, multi-morbid conditions (usually involving polypharmacy), and regular monitoring for progressive dementia changes, due to a shortage of primary care physicians. Others worried that patients might be less forthcoming with future medical or health complaints, if their sense of trust is damaged. Therefore, family physicians gladly accepted the fact that specialists willingly played the "bad guy" to maintain on-going family physician-patient contact.

Our findings suggest that some family physicians need additional training and support to address and screen for driving safety and competency. CANDRIVE is in the process of developing a rapid screening tool that can be used in the primary care setting to determine who is safe/unsafe to drive, or who needs more in-depth evaluation (i.e., specialized on-road assessment).⁽¹⁷⁾ Until this tool is developed, physicians can use *The Driving and Dementia Toolkit*—a systematic checklist that also provides coaching on disclosure of driving cessation to patients who are found to be unsafe drivers.^(18,19)

Despite recognition of the importance of education, counselling, and referral to home- and community-based support services to address patients' and family caregivers' evolving physical and psychosocial needs, this aspect of care deviated the most from clinical practice guidelines.^(10,13,14)

While lack of time in the standard 10–15 minute primary care office visit and inadequate financial reimbursement were cited as barriers in the provision of patient and caregiver education and support,^(20–22) our study also demonstrated that fragmentation in the availability and/or access to home care and social support services, and physicians' perceived compromised credibility when home-based services are suboptimal, were also significant barriers. As described in earlier reports, our hospital-based specialists were also more knowledgeable than family physicians about available social and community-based resources.^(10,11) However, their referral rates to psychosocial supportive services, as well as their European and American counterparts, could be vastly improved.^(9–11) Despite practice guidelines' recommendations, our study's physicians' referral rates to Alzheimer's Society chapters were also much lower than to home health agencies and day programs.^(16,13,23) These low referral rates may reflect some physicians' beliefs that practical home supports are more important than educational or psychosocial support services, and/or they have limited knowledge of the role and programs provided by voluntary organizations. Many physicians also recognized that many family caregivers, even with counselling and encouragement, will not seek help until they are faced with a crisis, such as caregiver burnout, an emergency room visit, or hospitalization. Finally, physicians often may not be aware when family caregivers are ready to accept help.^(21,22)

In this study, shared and collaborative care were two categories of proposed strategies to optimize the delivery of dementia care. Our family physicians, who had long-standing relationships with their specialist colleagues and to whom they often referred to, described the existence of

shared dementia care. These dyads, as concurred by a recent Scottish survey, were clear about their role in dementia care and felt that it was appropriately shared.⁽²³⁾ Physicians agreed that tools, such as standardized referral forms and algorithms (created by specialists) to assess and diagnose dementia and initiate and monitor response to cholinesterase inhibitors, enhanced quality of patient care and fostered two-way communication between physician groups.⁽²⁴⁾

As previously cited in the literature and echoed by our physicians, a multi-disciplinary team approach is crucial in managing both patients' and caregivers' evolving health and social care needs, as dementia progresses. In the last decade, emerging evidence suggests that collaborative care management delivered by care/case managers (usually advanced practice nurses or social workers) using standardized tools, protocols, and guidelines for chronic conditions such as diabetes, coronary heart disease, and congestive heart failure,⁽²⁵⁾ may also enhance dementia care.⁽²⁶⁾ One randomized controlled trial demonstrated that case management, led by an advanced practice nurse integrated within primary care and in collaboration with family physicians, various multi-disciplinary team members, and family caregivers, significantly improved quality of care for BPSD. Intervention patients had fewer BPSD symptoms than augmented care patients, despite significantly reduced use of antipsychotics and sedative-hypnotics, and intervention caregivers reported significant improvements in stress and depression.⁽²⁷⁾

Another strategy proposed to build capacity and optimize the diagnosis and primary management of dementia includes integration of interprofessional memory clinics within primary care practices, as described by Lee and colleagues.⁽²⁸⁾ A third strategy involves greater collaboration between primary care providers and community agencies, such as the Alzheimer's Society, and an expanded network of providers.⁽²⁹⁻³¹⁾ Therefore, delegating time-consuming aspects of dementia care, such as patient/caregiver education and support, referrals to home- and community-based support services, non-pharmacologic management of behavioural disturbances, and home and driving safety assessments^(7,12,21-22,24) to other professionals, allows physicians to focus on managing medical issues, which they feel better equipped to carry out.^(12,13,32)

Several limitations of this exploratory study warrant discussion. Our participants were drawn from urban, academic, and community teaching hospitals, and therefore not likely reflective of community-based physicians practicing in rural or remote settings. Initiatives that were implemented to optimize dementia care were jurisdiction-specific, and organized mainly around the Greater Toronto area. While dementia disclosure was not specified in our interview discussion guide, some physicians mentioned their unease in this important aspect of dementia care. Selection bias was likely a major factor, and we may have only captured the attitudes of physicians who are more dedicated and interested in geriatrics and, therefore, more willing to discuss dementia care. While

our sample size was sufficient for this exploratory study, it could be further strengthened by conducting additional interviews with physicians from non-urban practice settings, exploring physicians' experiences in dementia disclosure, and determining what constitutes optimal dementia care from the perspectives of persons with dementia and their informal caregivers.

CONCLUSION

Both family physicians and specialists acknowledged that the former group is now more confident in diagnosing and initiating/monitoring response to medications for common forms of dementia than a decade ago; and they agreed on care management issues that warranted specialist involvement. However, there were still gaps in dementia care, particularly with respect to patient and caregiver education and support, and driving cessation. Future research could further explore physicians' and other multi-disciplinary team members' perceived roles and responsibilities, and work satisfaction within a health-care system that is continuously evolving to meet the challenges of providing care to frail older adults with complex care needs, irrespective of cognitive status.

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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