

Screening for Dementia: First Signs and Symptoms Reported by Family Caregivers

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There is an average delay of 20 months between the first recognition of symptoms of Alzheimer's disease or a related disorder (ADRD) and the seeking of physician help. One reason for this delay is tendency for families to miss early symptoms until the onset of behavioural disturbances. Families may provide more timely accounts with prompted questions. It is important to diagnose cognitive impairment early since there are potential benefits to early treatment. The purpose of this article is to help guide caregivers in identifying a list of symptoms that reflect first indicators of ADRD, based on a study of 68 spouse caregivers of patients with ADRD.

Key words: Alzheimer's disease, dementia, caregivers, diagnosis, primary care

Introduction

As with all aging societies globally, the proportion of the Canadian population with a diagnosis of Alzheimer's disease or a related disorder (ADRD) is expected to more than double within a generation, with estimates ranging from 750,000 to 1 million by the year 2035.^{1,2} Most cases of ADRD are initially assessed in a primary care setting,² and by 2031, it is projected that each Canadian family physician will "have 20 to 40 patients with dementia in his or her practice and 4 to 8 new patients developing dementia each year."³ The Canadian Consensus Conference on Dementia emphasized the importance of early recognition of ADRD through active screening and case finding.²⁻⁴ The benefits of early diagnosis include the potential maintenance of function through the optimal use of therapeutics and opportunities to be involved in decision making regarding long-term care.^{5,6}

However, the literature reports that

underdiagnosis of ADRD in primary care settings is a common problem, ultimately affecting social and medical management.^{7,8} Reasons for underdiagnosis include a range of complex factors such as a lack of definitive tests and the wide variability of symptoms that can indicate ADRD.⁹ In a 2003 qualitative study by Iliffe *et al.*, general practitioners agreed on the benefits of early diagnosis but did not agree on best practices for ADRD screening (formal vs. opportunistic screening).¹⁰ This study underscores the interest and intent to diagnose ADRD as early as possible but the lack of consensus regarding how to best implement a screening program in a primary care setting.

Family Members and Recognition of First Indicators

According to the Canadian Medical Association, "dementia is diagnosed when acquired cognitive deficits are sufficient to interfere with social or occupational functioning in a person without

depression or clouding of consciousness."¹¹ Because family members and friends have access to such everyday information, their concerns about early indicators of dysfunction should be sought out and taken seriously.¹² In fact, the Canadian Consensus Conference on Dementia states that either objective indicators of decline or family confirmation is indicated to pursue diagnostic testing.² This suggests that family confirmation is an early, critical element in the screening process. However, family members may not notice or understand early signs, which can often be very subtle and explained by a number of other factors, such as physical illness. Two studies found that there was a mean delay of 20–21 months between the first incidence of family recognition of symptoms and the diagnosis.^{13,14} A more rigorous study by Drebing *et al.* triangulated data from interviews, questionnaires, and medical records to arrive at a mean delay of 31 months between first recognition and seeking primary care assistance (according to medical records, which were found to be the most reliable data source).¹⁵ According to the medical records, neurologists were first approached in 53% of the cases and primary care physicians in 23%. Ultimately, a diagnosis was made by a neurologist in 85% of the cases, an average of 5.6 years following the first recognition of symptoms.¹⁵

The delay between first recognition and seeking help may be partially attributed to difficulties that family members have in identifying first indicators as a problem, especially when the patient is primarily engaged in the repetitive and overlearned tasks of homemaking.¹⁶ Delay may also be related to not noticing or ignoring subtle clues until symptoms progress to the level of behavioural disturbances or a "decisive moment" occurs.¹⁷⁻¹⁹ A decisive moment is a sudden, alarming event that is recognized as a significant indicator of decline, usually involving a crisis (e.g., becoming seriously lost while driving) or a precipitous deterioration in function. The use of a structured list of symptoms may improve validity in the recall of first ADRD indi-

cators by family members.²⁰ The delay in reporting symptoms to a physician may also be related to the family member's relationship to the patient; in one study, spouses accounted for 73% of the family members who first recognized ADRD symptoms.¹⁶ Adult children who are providing care to a parent or parent-in-law may be less likely to witness or notice early symptom of ADRD due to lack of daily and consistent exposure to the patient's day-to-day behaviours. Taken together, these results suggest that primary care physicians must maintain a "high index of suspicion for dementia"² and solicit family member accounts of symptoms through skilled questions or prompts. The purpose of this article is to provide interview guidelines based on the results of a large qualitative study in which 68 spouse caregivers recounted the first indicators of ADRD, eventually leading to a diagnosis.

The Spouse Caregiving Study

The Spouse Caregiving Study was a mixed methods research project conducted from 1997 through 2002 with 68 spouse caregivers located in the Washington, DC, metropolitan area (National Institute on Aging grant R29 AG13019).²¹ Caregiver informants were actively providing care for at least 1 year to a spouse (or equivalent) with ADRD who required daily help with self-care. Narrative data were collected through the use of three home interviews scheduled 2 weeks apart. All spouse caregivers were asked to describe the first indications that something was wrong with the impaired husband or wife, even if the indicator was not recognized as such at the time.

Qualitative data were initially coded manually using a grounded theory approach^{22,23} until key phrases or words were identified. These phrases were used to automatically search and code the entire database. Using a constant comparison method, all coded text was manually analyzed for the purposes of revising codes, reducing data, and developing categories of "first symptoms." Rigour was maintained using accepted practices for qualitative research, includ-

Table 1: Early Indications of Alzheimer's Disease or a Related Disorder

Increased absentmindedness or forgetfulness
Need to be given same information more than once
Problems with tasks involving math or financial calculations
Change in spending habits
Change in attitude or personality (quieter, angry, argumentative, insensitive, fearful, suspicious, or lacking in judgment)
Change in driving habits or ability
Increase in minor damage to car or number of moving violations
Lack of interest in former pastimes or hobbies
Reduced level of involvement in household or work duties
Getting lost while driving, walking, or on public transportation
Difficulty concentrating
Questionable judgment or engaging in unsafe behaviour
Problems expressing a thought, reading, writing, or speaking

ing data triangulation and the use of multiple coders.^{23,24}

Caregiver informants participating in the study were mostly white females (57.4%, n = 39), in good health, who lived alone with the spouse and had been providing care for an average of 4.9 years. White males comprised 27.9% (n = 19) of the group. Ten caregivers identified themselves as black (three males and seven females).

Early Indicators

Categories of early signs involved forgetting or losing things; having trouble with higher-level tasks (especially involving math or assembly); reducing former levels of engagement in hobbies, interests, or home responsibilities; problems with driving; difficulty with reading, writing, or speaking; and changes in attitude or personality. Each is described more fully below and reflected in the list of recommended questions for family members (Table 1).

Forgetting or Losing Things

In the literature, caregivers are most likely to name forgetfulness as a first indica-

tor of ADRD,²⁰ and this finding was reflected in the Spouse Caregiving Study. Caregivers described a few manifestations of forgetfulness, including needing to be told the same information repeatedly ("absentmindedness"), an inability to recall names of frequently seen family members, mistaking the relationships of one family member for another ("thought our son was our nephew"), and forgetting that a meal had already been eaten.

Trouble with Higher-Level Tasks

Caregivers in the Spouse Caregiving Study recounted their spouse's problems with higher-order cognitive tasks (especially involving math or assembly, e.g., calculating taxes, keeping time sheets at work) and new learning ("couldn't learn to use a Windows operating system"; "he couldn't catch onto a simple card game"). Spouses talked about new patterns in donations ("gave money to every organization that requested it, even groups he formerly opposed"), spending habits ("purchased a 42-inch television for our tiny apartment"), and money management ("wrote a check for the highest dol-

lar amount on any mailed item, whether it was a bill or not"; "found out he was hiding the bills instead of paying them"). Sometimes these problems were first noticed when productivity or accuracy declined at work. Other higher-level tasks that alerted the caregiver to problems included an inability to assemble simple items, such as not being able to put a blender back together after washing.

Reduction in Former Hobbies, Interests, or Home Responsibilities

Spouses suspected problems when a husband or wife lost interest in former hobbies or pastimes ("she stopped writing letters to her sister"; "he used to love taking photographs, but after one trip he didn't even look at the pictures") or neglected duties previously assumed at home, including cooking and cleaning. In many cases, these pastimes or responsibilities were replaced by excessive television viewing ("she was absorbed by the TV for hours all day").

Problems with Driving

The literature is clear on driving accidents and getting lost while driving as typical indicators of cognitive decline,^{16–18,20} and the spouses in this study reflected those observations ("she was gone for 5 hours"). However, problems emerged even earlier with a series of smaller signs ("over time, I noticed his car had many scratches and small dents"; "when our insurance bill doubled, she confessed to several moving violations").

Difficulty with Reading, Writing, or Speaking

A lack of reading comprehension, difficulty with writing, or a lack of concentration alerted spouses to an emerging problem. Spouses also spoke of garbled

Key Points

There is an average delay of 20 months between the first recognition of symptoms of Alzheimer's disease or a related disorder (ADRD) and diagnosis.

According to the Canadian Consensus Conference on Dementia, primary care physicians must maintain a high index of suspicion for dementia.

Family confirmation is an early, critical element in the process of screening for dementia.

Family members (especially adult children) may not notice or understand early signs, which can often be very subtle and explained by a number of other factors.

In addition to forgetting or losing things, early signs also include problems with higher-level tasks, reducing former levels of engagement, problems with driving, difficulty with reading, writing, or speaking and changes in attitude or personality.

speech or excessive word-finding problems, which were found to be the most frequent first indicators of frontotemporal lobar degeneration in a study by Diehl-Schmid *et al.*²⁵

Changes in Attitude or Personality


Spouses spoke of increased anger, suspicion, insensitivity, and arguments as signs that, in retrospect, indicated cognitive changes associated with ADRD. Problems exhibited as a passenger in a car also served as first indicators ("he yelled at other drivers"; "he wanted me to bash our car into someone who had just cut us off").

Guidelines for Interviewing Family Members

Table 1 provides a list of symptoms that reflect the first indicators described in the Spouse Caregiving Study. The list is not intended as a questionnaire but, rather, as a guide to questions that could elicit family reports or a list of alerts to keep in mind as family members provide a current status report. In the hands of a primary care physician who is alert to the

potential for ADRD, this list may be useful for identifying those patients who could benefit from further screening and diagnostic tests.

Conclusion

Family confirmation is an early, critical element in the process of screening for dementia. However, family members may not notice or understand early signs, which can often be very subtle and explained by a number of other factors, such as physical illness. Primary care physicians may use questions from the Spouse Caregiver Study to elicit a current status report from caregivers, which may lead to earlier detection of ADRD. 

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Clinical Pearls

Include family members in a pro-active approach to screening for dementia.

Use prompted questions to screen for early signs of dementia.

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