ORIGINAL RESEARCH

The Lost Years: Delay Between the Onset of Cognitive Symptoms and Clinical Assessment at a Memory Clinic

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DOI:https://doi.org/10.5770/cgj.21.297

ABSTRACT

Background

Early assessment of cognitive symptoms is an issue in geriatrics. This study investigated the delay from the onset of cognitive symptoms to initial clinical assessment and its associations with patients' sociodemographic and clinical characteristics.

Methods

This is a cross-sectional retrospective study using medical chart review of 316 patients referred for assessment to a university-affiliated memory clinic. Symptom duration was self-reported by patients/carers. Severity of symptoms assessed by the MoCA and FAST instruments was compared according to delay duration (≥3 years vs. <3 years) using chi-squared tests. Logistic regression was used to determine the association between patients' characteristics and long symptom duration (≥3 years).

Results

At the initial assessment, 29.4% of patients reported experiencing cognitive symptoms for ≥3 years. They were more likely to have MoCA scores ≤17 (47.8 vs. 34.1%; p=.023) and FAST scores ≥5 (21.5 vs. 10.8%; p=.012). They were also significantly older than 75 years (75-84 yr: OR=2.22 [95%CI: 1.11–4.41]; ≥85 yr: 4.36 [2.08–9.11]), presented more depressive symptoms (2.37 [1.40-4.02]), and were less likely to live alone (0.55 [0.31–0.96]).

Conclusions

A significant proportion of patients had cognitive symptoms for years when initially assessed, which delayed diagnosis and management. Stigma, depression, and compensatory help from carers may contribute to this delay.

Key words: memory clinic, symptom duration, referral, dementia, mild cognitive impairment

Introduction

Early assessment of cognitive decline is an important issue in geriatrics since timely management has many advantages including treatment of reversible causes (e.g., depression), benefits from pharmacological interventions in early-dementia stages, and opportunity to plan for the future.[1] Yet, at diagnosis, cognitive changes have often been noticed for a long time, with mean symptom durations varying from 1.2 to 3.1 years in memory clinics of different countries.[2-9] Data also suggested that, the longer the symptom duration at diagnosis, the more severe the cognitive impairment,[2,3,10] which stresses the importance of gaining insight into that matter in order to develop strategies promoting shorter delays.

Reasons for delay have not been extensively investigated from a quantitative perspective. To our knowledge, there are only two studies which showed that delays were longer in women[3,10] and with increased age.[3] Qualitative studies are more common, though, and revealed that the process of discounting and normalizing cognitive decline by both patients and carers are important underlying factors.[11-13] In several cases, the involvement of health professionals has been ultimately triggered by crisis situations.

As data on this important topic remain very limited, especially in Canada, we undertook a study based on medical chart reviews of community-dwelling patients from a university-affiliated memory clinic in Quebec. The study aims to: 1) portray symptom duration reported at initial assessment; 2) determine whether long delay (≥3 years) is actually associated with more severe cognitive impairment; and 3) explore which

patients' sociodemographic and clinical characteristics could underlie long delays.

METHODS

This retrospective cross-sectional study is based on data from medical charts of patients who had their initial visit at the Memory Clinic of the Institut universitaire de gériatrie de Montréal (IUGM) between October 1st, 2012 and June 26th, 2014 (n=411). Sixty-four were excluded as they were already diagnosed with dementia or were living in nursing homes upon referral. We further excluded nine patients with incomplete initial assessments and 22 with time from referral to initial visit ≥6 months, mostly because they were not available when contacted for appointment. Final sample thus included 316 patients. The study was approved by the IUGM Medical Director in accordance with article 19.2 of the *Quebec Act Respecting Health and Social Services*.

Medical charts were reviewed by a physician. Data were primarily collected from the standardized form used for the initial assessment and filled out by the attending physician (geriatrician, neurologist or geriatric psychiatrist). As all patients of the Memory Clinic are asked to be accompanied by a family member or a caregiver at each appointment, interviews are virtually all conducted with the patient-carer dyad in order to ensure the reliability of the information collected.

Cognitive symptom durations in months/years were collected from the initial assessment form. The attending physician specifically records this information using semi-structured questioning of patient-carer dyads about the history of cognitive symptoms, including when they first noticed that something was amiss. In most cases, physicians recorded symptom durations as being 6 months, 1 year, 2 years, 3 years, and so on. Delays ≥3 years were deemed 'untimely' by the geriatricians of the Memory Clinic.

Severity of cognitive impairment was determined using the Montreal Cognitive Assessment (MoCA) and the Functional Assessment Staging Test (FAST).[14,15] MoCA scores were categorized as no (27–30), mild (18–26), moderate (10–17), and severe impairment (<10) (www.mocatest.org). When the Mini-Mental State Examination was used instead of MoCA, scores were translated using conversion tables.[16,17] Dementia-related functional impairment was categorized based on FAST scores as subjective complaints (stage 2), mild cognitive impairment (stage 3), mild dementia (stage 4), and moderate or severe dementia (stages ≥5).[14] Clinical diagnoses were based on standard guidelines, notably the NIA-AA criteria.[18,19] Subjective cognitive impairment was diagnosed in patients perceiving cognitive decline without objective evidence of cognitive or relevant functional impairments.

Patients' characteristics included age, sex, level of education (<8, 8–12, >12 years), living arrangement (living alone or not), the number of prescribed drugs (0–3, 4–9, ≥10), help for activities of daily living provided by the local community service centre, self-reported depressive symptoms, and self-awareness of cognitive impairment. The referring professional (general practitioner or others) and the time from referral to appointment at the Memory Clinic (months) were also noted.

Chi-squared tests were used to compare MoCA score categories, FAST stages, and final diagnosis between groups (delay ≥3 vs. <3 years). Logistic regression was used to determine the odds ratio (OR) for long delay (≥3 years) according to relevant patients' characteristics. Characteristics were entered stepwise using a forward selection approach. Analyses were conducted using IBM SPSS Statistics 24; $p<.05$ was considered significant.

RESULTS

Medical charts pertained to 210 women and 106 men aged 63 to 101 years living mostly with family members or carers (Table 1). Virtually all patients (91.5%) were referred to the Memory Clinic by a general practitioner, and 81.6% were seen in <3 months. At initial visit, MoCA scores revealed that 87.5% of patients actually had some level of cognitive impairment (MoCA ≤26). Following assessment, 80.4% of patients were diagnosed with either mild cognitive impairment (MCI), Alzheimer's dementia or mixed dementia, while 7.6% had subjective cognitive impairment and 12.0% other causes of cognitive disorders.

Ninety-three patients (29.4%) reported experiencing cognitive symptoms for ≥3 years, the longest being 14 years (mean±SD; 2.2±1.4 years). Only 7.6% had symptoms for <1 year and 38.0% for <2 years. Patients with symptom duration ≥3 years were more likely to have MoCA scores ≤17 (47.8 vs. 34.1%; $p=.023$) and FAST scores ≥5 (21.5 vs. 10.8%; $p=.012$). Results from logistic regression indicated that older patients, those reporting depressive symptoms, and those who did not live alone were more likely to report long symptom duration (Table 2).

DISCUSSION

Patients of our Memory Clinic often had cognitive symptoms for years when initially assessed and as expected, also had more severe cognitive and dementia-related functional impairments than those who were assessed within 3 years of symptom onset. Few patients' characteristics were associated with an increased risk of long delay which included age, living arrangement, and depressive symptoms.

Symptom durations in the present study are consistent with average data (1.2–3.1 years) from memory clinics of several countries.[2-9] Interestingly, our findings are very similar to those recently reported in Saskatchewan where symptom duration was 1.9±1.8 years (mean±SD) at diagnosis, ranging from 0 to 12 years.[2] In the latter, symptom duration was also found to be negatively correlated with the Modified Mini-Mental State Examination score, consistent with our data.

Delays before reaching the memory clinic sum up three components: 1) time to seek medical help; 2) time for referral;

TABLE 1.
Sociodemographic and clinical characteristics of patients referred to a memory clinic for clinical assessment

Characteristics	*All*	*Symptom Duration*		*p-value*[a]
		<3 years	*≥3 years*	
Sample size	316	223	93	
Women, n (%)	210 (66.5)	145 (65.0)	65 (69.9)	0.40
Age groups, n (%)				<0.001
<75 years	89 (28.2)	75 (33.6)	14 (15.1)	
75–84 years	143 (45.3)	100 (44.8)	43 (46.2)	
≥85 years	84 (26.6)	48 (21.5)	36 (38.7)	
Level of education, n (%)[b]				0.86
<8 years	72 (22.9)	51 (23.0)	21 (22.8)	
8–12 years	119 (37.9)	86 (38.7)	33 (35.9)	
>12 years	123 (39.2)	85 (38.3)	38 (41.3)	
Living alone, n (%)	105 (33.2)	81 (36.3)	24 (25.8)	0.07
Getting formal help for ADL, n (%)[c]	52 (16.5)	29 (13.1)	23 (24.7)	0.01
Number of prescribed drugs, n (%)				0.04
0–3	54 (17.1)	37 (16.6)	17 (18.3)	
4–9	181 (57.3)	137 (61.4)	44 (47.3)	
≥10	81 (25.6)	49 (22.0)	32 (34.4)	
Depressive symptoms, n (%)	160 (50.6)	100 (44.8)	60 (64.5)	0.001
Self-awareness of cognitive impairment, n (%)	251 (79.4)	179 (80.3)	72 (77.4)	0.57
Cognitive impairment severity, n (%)[d]				0.14
Normal	39 (12.5)	30 (13.6)	9 (9.8)	
Mild	154 (49.4)	115 (52.3)	39 (42.4)	
Moderate	97 (31.1)	62 (28.2)	35 (38.0)	
Severe	22 (7.1)	13 (5.9)	9 (9.8)	
Stages of dementia-related functional impairment, n (%)[e]				0.02
Subjective complaints, no impairment	77 (24.4)	59 (26.5)	18 (19.4)	
Mild cognitive impairment	69 (21.8)	55 (24.7)	14 (15.1)	
Mild dementia	126 (39.9)	85 (38.1)	41 (44.1)	
Moderate or severe dementia	44 (13.9)	24 (10.8)	20 (21.5)	
Final diagnosis, n (%)				0.18
Subjective cognitive impairment	24 (7.6)	19 (8.5)	5 (5.4)	
Mild cognitive impairment	107 (33.9)	82 (36.8)	25 (26.9)	
Alzheimer's disease	78 (24.7)	52 (23.3)	26 (28.0)	
Mixed dementia	69 (21.8)	41 (18.4)	28 (30.1)	
Others[f]	38 (12.0)	29 (13.0)	9 (9.7)	

[a]Data were analyzed by chi-squared tests.
[b]n=314.
[c]As provided by the local community service centre; n=315.
[d]Based on the Montreal Cognitive Assessment score; n=312.
[e]Based on the Functional Assessment Staging Test.
[f]Other diagnoses include vascular dementia, Lewy's bodies dementia, semantic/frontotemporal dementia, Parkinson's disease dementia, unspecified dementia, and cognitive impairment related to non-neurodegenerative disease (e.g., depression, alcoholism).
ADL = activities of daily living.

TABLE 2.
Results from the logistic regression model examining the association between the patients' characteristics and long symptom duration (≥3 years)

Characteristics[a]	*OR (95% CI)*	*p-value*
Age groups		
<75 years	1.00	
75–84 years	2.22 (1.11-4.41)	0.024
≥85 years	4.36 (2.08-9.11)	<0.001
Depressive symptoms	2.38 (1.40-4.02)	0.001
Living alone	0.55 (0.31-0.96)	0.036

[a]Patients' sociodemographic and clinical characteristics were entered stepwise. Other characteristics did not enter the model.

and 3) time from referral to appointment. That last component was short in the present study (<3 months) and comparable with that from Ontario and European countries.[1,20] The other two components cannot be assessed from medical charts. However, according to previous studies, delays are mainly due to the first component.[4,7] The significant stigma associated with dementia and the belief that cognitive changes are part of normal aging are thought to be major reasons for delay.[1,12,13] This may explain why older age was the strongest predictor of long delay in the present study, as well as in that of Cattel *et al*.[3] This is also consistent with one study showing that the oldest patients of a memory clinic were also those initially presenting more severe cognitive impairments.[21] In a qualitative study, it was reported that some carers recognized that something was amiss, but their intervention was first to provide compensatory help instead of seeking medical involvement.[11] Such observation may explain why in the present study, patients living with family members or carers were more likely to report long symptom duration. A similar observation has been made by Swanwick *et al*.,[10] where patients living with an adult child had greater functional impairment at presentation to a memory clinic than those living alone or with a spouse.

Cognitive decline and depression are frequent coexisting conditions in patients of memory clinics. Yet, the present study is the first showing that depressive symptoms could delay the initial visit. This finding is of concern, as late-life depressive symptoms could be prodromal to dementia,[22] and have been associated repeatedly with higher rate of progression from MCI to dementia.[23-25] Whether depressive symptoms increase time for seeking medical help, time before referral, or both, should be investigated in future research. In addition, our findings surely underline the urgent need for strategies that would lead to shorter delays. In fact, recommendations have been made previously for public and professional education in order to overcome the stigma and inform on the advantages of coming forward early when people first notice cognitive changes.[1] Of note, the need for continuing education for health-care providers has been specifically targeted in the *Alzheimer Plan* of the Quebec Ministry of Health and Social Services.[26]

Limitations of the present study firstly include its cross-sectional retrospective design. Also, estimates of symptom duration relied entirely on the information provided by patient-carer dyads, which is inevitably approximate. Finally, our findings likely reflect specific sociocultural and organizational factors in Quebec and may not be generalizable to other provinces or countries.

CONCLUSION

The present study highlighted that most patients assessed at our Memory Clinic have perceived cognitive symptoms for years before diagnosis, suggesting that we missed a large window of opportunity for early management. Stigma, depression, and compensatory help from carers may underlie this delay. Public and professional education is warranted.

ACKNOWLEDGEMENTS

No funding has been received for this work. JSC received a summer scholarship from the Fondation de l'Institut de gériatrie de Montréal and the Council of Physicians, Dentists and Pharmacists of the Institut universitaire de gériatrie de Montréal.

CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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