

Diagnosing cognitive impairment and dementia in primary health care – a more active approach is needed

MINNA LÖPPÖNEN[1,2], ISMO RÄIHÄ[3,5], RAIMO ISOAHO[1,2], TERO VAHLBERG[4], SIRKKA-LIISA KIVELÄ[1,6]

[1]Institute of Clinical Medicine, General Practice, University of Turku, Finland
[2]Härkätie Health Centre, Finland
[3]Institute of Clinical Medicine, Geriatrics
[4]Department of Biostatistics, University of Turku, Finland
[5]Turku Health Centre, Finland
[6]Satakunta Central Hospital, Finland

Address correspondence to: M. Löppönen, Institute of Clinical Medicine, General Practice, University of Turku, Lemminkäisenkatu 1, FIN-20014 Turku, Finland. Fax: (+358) 2 333 8439. Email: minna.lopponen@utu.fi

Abstract

Objective: to determine the documentation rate of dementia in primary health care, the clinical characteristics of patients with documented and undocumented dementia, and the diagnostic evaluations made in cognitive impairment.
Design: cross-sectional population-based study with a retrospective review of medical history.
Setting: primary health care in the municipality of Lieto, Southwestern Finland.
Subjects: all the inhabitants aged 64 and over in Lieto. Participation rate 82%, numbers = 1260.
Measurements: assessment of dementia according to DSM-IV criteria, and severity according to Clinical Dementia Rating. Possible documentation of dementia and evaluations done were reviewed from primary health care medical records.
Results: 112 patients with dementia were found. The sensitivity of the general practitioners' judgment of dementia was 48.2% and the specificity 99.6%. The documentation rate of dementia was 73% in severe, 46% in moderate and 33% in mild dementia. A greater proportion of the patients with undocumented dementia were male ($P = 0.003$), lived at home ($P = 0.003$), coped better with the instrumental activities of daily living ($P = 0.006$), had more depression ($P = 0.029$) and milder dementia ($P = 0.005$) than patients with documented dementia. Thyroid stimulating hormone was measured in 51% of the patients with suspected memory impairment or dementia, B12 vitamin in 20%, and serum calcium in 18%. Twenty-eight per cent of the patients had been tested for cognitive function, 68% for depressive symptoms, and 88% for social abilities. Forty-two per cent of patients were referred to a specialist, 32% of patients who were over 75 years.
Conclusions: less than half of the patients with dementia had their diagnosis documented in primary care medical records. Documentation increased in more advanced dementia. The diagnostic evaluations for reversible causes of dementia were insufficient in primary care, and they were done at a late phase of cognitive impairment.

Keywords: *dementia, primary care, diagnosis, population-based*

Introduction

The prevalence of dementia in a population has been shown to be bigger than the prevalence of dementia detected by local general practitioners (GPs) working in the community [1–4]. The fact that the population is ageing with increasing numbers of patients with dementia and the current emphasis on early detection of cognitive impairment and dementia, have enhanced the importance of recognising patients with cognitive decline more actively in primary health care [5–8]. GPs are said to be well positioned to notice the possible cognitive decline of their patients because of the continuity of care [1, 2, 5, 9], and primary health care contacts (GP visits, district nursing, and home help services) appear to be the major potential source for increasing the rate of dementia case detection [9]. GPs in many countries, as in Finland where this study was carried out, also have a gatekeeper role for

specialist evaluation and treatment [1, 5] emphasising their key role in the diagnostic process of dementia.

Even though there are reports on low usage of standardised psychometric tests in diagnosing dementia in primary health care [10, 11], little is known in a population-based setting how the GPs actually evaluate their patients with dementia. It seems that patients with documented cognitive impairment are more likely to be evaluated for reversible causes than patients without documentation [12], but the recommended laboratory tests are not routinely performed [10–12].

The objectives of our study were to determine the documentation rate of dementia in primary health care, identify the demographic and clinical factors associated with patients with documented and undocumented dementia, and describe the diagnostic evaluations made for patients with suspected cognitive impairment.

Methods

This study was part of a longitudinal epidemiological study carried out in the semi-industrialised municipality of Lieto in Southwestern Finland in 1990–1991 and 1998–1999. The study was designed to investigate the prevalences of cardiovascular, respiratory and other common diseases in an unselected population aged 64 and over. In this study, we used cross-sectional data collected between March 1998 and September 1999. Written informed consent was obtained from all the participants or their representatives. The Joint Commission on Ethics of the University of Turku approved the study protocol.

All residents born in 1933 or earlier living in Lieto on 16 February 1998 ($n = 1596$; 666 men and 930 women, 12% of the population) were invited to the Lieto Health Centre in random order. Of those eligible, 63 died before they could be examined, and 273 refused or did not respond, leaving 1260 participants, 533 men and 727 women. The participation rate was 82%.

The study protocol consisted of an interview ($n = 1260$), a visit to the laboratory ($n = 1254$) and a clinical examination ($n = 1252$). In addition to the demographic data, the interview comprised items on functional abilities, memory complaints and health behaviour, history of possible depression and dementia, and measurements of vision and hearing. Each interview lasted approximately 90 minutes and was carried out by one of two specially trained nurses of the research team. Numerous laboratory tests, electrocardiogram and chest radiogram were performed during the visit to the laboratory. All information from the interview and medical records, as well as the results of the laboratory tests, were available in a clinical examination which lasted approximately 60 minutes, and was carried out by either of the two research physicians (ML or RI), both experienced GPs. People living in institutions ($n = 63$) or being treated in hospitals during the study ($n = 29$) were examined in the respective places. Thirty-nine home visits were also made. During the clinical examination, the assessments of depression and dementia were made according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders-fourth edition (DSM-IV), Finnish version 1997 [13].

During 1998, 8 doctors (7 GPs and 1 doctor during internship) worked in the Lieto Health Centre. Five of seven GPs had been working over 10 years in the same municipality, and 4 doctors were women.

Diagnostic procedures for dementia

A two-stage design was applied to assess dementia. In the first stage, the Mini-Mental State Examination (MMSE) [14] was performed to screen cognitive functioning ($n = 1260$). Criteria for the second stage were: (1) MMSE sum score 0–23 ($n = 149$); (2) previous history of dementing disorder with MMSE sum score 24–30 ($n = 9$); (3) any clinical suspicion of dementia in interview or clinical examination with MMSE sum score 24–30 ($n = 14$).

Caregivers were invited to attend the interviews and 68 participated. The nursing staff were interviewed in the case of institutionalised or hospitalised patients. The interview was semi-structured and covered the items of the Hachinski ischaemic scale [15] and the Clinical Dementia Rating Scale (CDR) [16], which were used in assessing the severity of the dementia. Finally, dementia was assessed according to the DSM-IV criteria including the CDR classes 1, 2 and 3 (mild, moderate and severe dementia), the diagnosis of possible Alzheimer's disease according to the NINCDS-ADRDA criteria [17], and the diagnosis of possible vascular dementia according to NINDS-AIREN criteria [18]. In cases of disagreement, a consensus was reached between the research physicians and the geriatrician (IR).

Review of medical records

Clinical information was collected from the primary care medical records for the maximum period ($n = 1260$) by one of the research physicians (ML or RI). According to the medical records, the patient was classified as having 'documented dementia' when the word *dementia* occurred in the patient's diagnosis list or in the text of a physician's notes ($n = 58$). Patients who were found to have dementia in the examinations, but no dementia diagnosis documented in the medical records, were classified as having 'undocumented dementia' ($n = 58$). Four patients who did not have dementia according to DSM-IV criteria but did have a diagnosis of dementia in their medical records were excluded from the analyses presented in Table 1. When there were notes on suspicion of cognitive decline or memory disturbance like *forgetfulness, poor memory* in the medical records, the patient was classified as having 'memory impairment' ($n = 37$). The diagnostic evaluation period was counted from the date when the memory impairment was first mentioned.

Table 1. Characteristics of persons with no dementia, and of those with dementia with the diagnosis either documented or undocumented in primary health care medical records

Characteristic	No dementia (1) *n* (%)	Undocumented dementia (2) *n* (%)	Documented dementia (3) *n* (%)	Overall *P*-value	2 *versus* 1 OR (95% CI)[a]	3 *versus* 1 OR (95% CI)[a]
Total number	1136 (91)	58 (5)	54 (4)			
Sex						
Women	646 (90)	32 (4)	44 (6)	0.003	0.9 (0.5–1.6)	3.3 (1.7–6.7)
Men	490 (93)	26 (5)	10 (2)		1	1
Age in years, mean (SD)	72.5 (6.1)	83.0 (7.1)	81.8 (6.9)	< 0.001	1.2 (1.2–1.3)	1.2 (1.1–1.2)
Marital status						
Married	703 (95)	17 (2)	19 (3)	0.270	0.6 (0.3–1.2)	1.3 (0.6–2.5)
Unmarried, widow or divorced	433 (85)	41 (8)	35 (7)		1	1
Educational level						
Six years or less	728 (89)	46 (6)	40 (5)	0.437	1.6 (0.8–3.1)	1.1 (0.6–2.1)
More than six years	408 (94)	12 (3)	14 (3)		1	1
Place of residence						
In an institution	7 (11)	21 (33)	35 (56)	< 0.001	40.3 (14.7–110.5)	146.4 (55.6–387.6)
At home	1129 (95)	37 (3)	19 (2)		1	1
MMSE sum score, mean (SD)[b]	27.7 (2.4)	17.0 (6.9)	12.7 (8.3)	< 0.001	0.6 (0.5–0.7)	0.6 (0.6–0.7)
ADL sum score, mean (SD)[c]	4.9 (0.5)	3.0 (1.9)	2.4 (1.8)	< 0.001	0.3 (0.3–0.4)	0.3 (0.2–0.4)
IADL sum score, mean (SD)[d]	8.1 (1.8)	2.6 (3.1)	1.2 (2.4)	< 0.001	0.6 (0.5–0.6)	0.4 (0.3–0.5)
Depression according to DSM-IV[e]						
Yes	207 (85)	24 (10)	12 (5)	0.003	2.9 (1.6–5.4)	1.2 (0.6–2.4)
No	887 (93)	31 (3)	39 (4)		1	1
Family history of dementia						
Yes	245 (90)	11 (4)	15 (6)	0.103	1.3 (0.6–2.6)	2.0 (1.1–4.0)
No	886 (91)	46 (5)	35 (4)		1	1
Visiting/being visited by someone						
Once a week or less	602 (89)	40 (6)	35 (5)	0.026	1.9 (1.0–3.6)	1.9 (1.0–3.5)
More than once a week	534 (94)	18 (3)	19 (3)		1	1

[a]Odds ratio and 95% confidence interval for patients with dementia after adjustment for age and sex; persons with no dementia as a reference group. For continuous variables the odds ratios are given per one unit increase.
[b]Mini-mental State Examination, range 0–30; higher score indicates better cognitive functioning.
[c]5 items of the Activities of Daily Living, range 0–5; higher score indicates better performance.
[d]9 items of the modified Instrumental Activities of Daily Living, range 0–9; higher score indicates better performance.
[e]Diagnostic and Statistical Manual – fourth edition.

Presented in Table 2 are the diagnostic evaluations of the patients who had complete data for the evaluation period and who were not detected in the first data collection in 1990–1991 ($n = 88$). The outpatients' visits to GPs were counted during the 24 months prior to dementia documentation, or during the 24 months prior to the clinical examination visit of this study if the diagnosis was not documented.

Statistical analyses

The associations between the dependent variable (persons with no dementia, patients with undocumented or documented dementia), and the explanatory variables were analysed using multinomial logistic regression with age and sex as covariates (Table 1) [19]. The results were quantified by calculating odds ratios (OR) with their 95% confidence intervals (95% CI). The differences between the patients with undocumented and documented dementia, as well as the differences in the referral rates (Figure 1), and evaluations recorded (Table 2), were tested using chi-squared test or Fisher's exact test, and two-sample *t*-test or Mann–Whitney U test in the case of continuous variables. *P*-values less than 0.05 were considered statistically significant. SAS software, version 8.2 (SAS Institute Inc., Cary, NC, USA) was used in statistical computations.

Results

Sensitivity and specificity of GPs diagnosing of dementia

In the examinations, 112 patients with dementia were found (49 with Alzheimer's disease, 41 with vascular dementia, 6 with Parkinson disease and dementia, and 16 with dementia caused by multiple other reasons), and 54 of them had dementia documented in their medical records. Four patients were diagnosed with dementia in the medical records, but the results in the examinations were negative. Thirty-seven patients had notes on cognitive impairment in their medical records and 32 of them had dementia. The sensitivity of the GPs judgment of definite dementia was 48.2%, and the specificity 99.6%. According to the severity of dementia, the documentation

Table 2. Diagnostic evaluations made in primary health care for patients with documented dementia and for those with cognitive impairment

Examination[a]	Documented dementia	Cognitive impairment	*P*-value
	N = 53	*N* = 35	
	n (%)	*n* (%)	
Blood cell count	51 (96)	28 (80)	0.026
Plasma sodium, potassium	45 (85)	24 (69)	0.068
Serum thyroid stimulating hormone	34 (64)	11 (31)	0.003
Serum B12-vitamin concentration	16 (30)	2 (6)	0.005
Blood glucose	37 (70)	23 (66)	0.686
Serum calcium	11 (21)	5 (14)	0.441
Serum creatinine	40 (75)	20 (57)	0.071
Serum ALAT[b]	20 (38)	7 (20)	0.077
Cognitive testing[c]	18 (34)	7 (20)	0.155
Assessment of depressive symptoms[d]	41 (77)	19 (54)	0.023
Assessment of social abilities[e]	47 (89)	30 (86)	0.681
Referral to specialist assessment	26 (49)	11 (31)	0.101
Neuroimaging (CT or MRI)[f]	25 (47)	10 (29)	0.081

[a]Laboratory tests taken 12 months prior or after, and testing and assessments made 12 months after the first note of memory disturbance in medical records; referral to specialist and neuroimaging without time limitation after the recording.
[b]Alanine aminotransferase.
[c]Cognitive testing made by using any structural test like Mini-mental State Examination.
[d]Depressive symptoms evaluated clinically or by using any structural questionnaire.
[e]Social abilities evaluated clinically or by using any structural questionnaire.
[f]Computer tomography or magnetic resonance imaging done in specialist clinics.

rates were 73% in severe, 46% in moderate and 33% in mild dementia.

If the wider concept 'memory impairment' (including definite dementia) was used, the GP's sensitivity to detect cognitive decline was 76.8%, and the specificity 99.2%. According to the severity of dementia, the documentation rates of memory impairment were 97% in severe, 71% in moderate and 66% in mild dementia.

According to age, the percentages of patients whose dementia was not detected at all in primary health care were 17% in patients aged 64–74 years, 22% aged 75–84 and 28% aged 85 years or over ($P = 0.594$) (Figure 1).

Patients with undocumented or documented dementia

The characteristics of patients with no dementia, and those of patients with dementia (either undocumented or documented) are seen in Table 1. Of the patients with undocumented dementia 55% were women, 29% had Alzheimer's disease, and 45% vascular dementia. The mean age was 83.0 years (SD 7.1), and the mean MMSE sum score was 17.0 (SD 6.9). Of the patients with documented dementia 81% were women, 59% had Alzheimer's disease, and 28% vascular dementia. The mean age was 81.8 years (SD 6.9), and the mean MMSE sum score was 12.7 (SD 8.3).

In the comparison between the dementia patients (Table 1), those with undocumented dementia were more likely to be male ($P = 0.003$); more depressed ($P = 0.029$) and with milder dementia ($P = 0.005$) than the patients with documented dementia. A greater proportion of the patients with undocumented dementia lived at home ($P = 0.003$), and coped better with the instrumental activities of daily living ($P = 0.006$). A smaller proportion

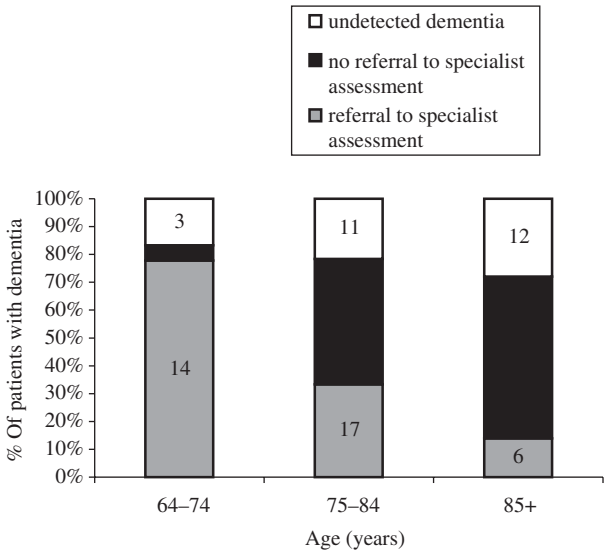

Figure 1. Proportion (%) of patients with dementia whose dementia was not detected in primary health care according to primary care medical records, proportion of those who were not referred to specialist assessment, and proportion of those who were referred to specialist assessment for cognitive impairment and dementia by age groups.

of patients with undocumented dementia had Alzheimer's disease than patients with documented dementia ($P = 0.001$). The difference between the groups in the prevalence of dementia was not statistically significant ($P = 0.061$).

The association between the GP contact rates (see Methods) and undocumented or documented dementia was analysed after an adjustment for sex, but the association was not significant ($P = 0.230$).

Diagnostic evaluations in primary health care

Thyroid stimulating hormone (TSH) was measured in 31% of the patients with memory impairment and in 65% of the patients with documented dementia, B12 vitamin in 6% and 30%, and serum calcium in 14% and 21%, respectively (Table 2). Cognitive function was tested in 28% of the patients, but depressive symptoms (68%) and social abilities (88%) were assessed in most of the cases. Forty-nine per cent of the patients with documented dementia and 31% of the patients with memory impairment were referred to a specialist (neurologist, geriatrician or psychiatrist), and in nearly all of these cases neuroimaging was performed. By patient's age, the referral rate fell from 78% among the patients aged 64–74 years to 45% among those aged 75–84, and to 14% among those aged 85 years or over ($P < 0.001$) (Figure 1).

Discussion

The population-based design and the high participation rate are the main strengths of this study as well as the study population being a representative sample of Finnish older people naturally located in a municipality. The modest participation rate of close caregivers in the interviews is the major limitation. However, the nursing staff were able to provide background information for the CDR in most of the cases of patients treated in the institutions. This, and the study design, may have caused some missing of mild dementia cases but probably affected to a small degree the prevalence of dementia, which compares favourably with the work of others [20, 21].

At the beginning of the 1960s only 13% of patients with dementia were known to be demented by their own GPs [4]. Twenty-five years later the rate of detection of possible or definite dementia by British GPs was 58%: 77% in severe, 61% in moderate and 50% in mild dementia [1]. Recently published studies from Linköping, Sweden [2] and Honolulu, Hawaii [3] still show quite low detection and documentation rates of cognitive impairment and dementia in primary care. In Sweden 26%, and in the United States 35%, of all dementia cases were documented: 60–80% in severe, 15–29% in moderate, and 21–24% in mild dementia. Our finding of the documentation rate of dementia (48% of all: 73% in severe, 46% in moderate and 33% in mild dementia) show that GPs are better able to detect their patients with dementia. If a wider concept of 'memory impairment' (including definite dementia) is used, the proportion of patients detected is quite high in our study (78% of all; 97% in severe, 71% in moderate and 66% in mild dementia). It should be noted, however, that over half of the patients did not receive targeted medical care for dementia from their family doctors, and of the mild dementia cases one third was missed, one third was suspected, and only one third diagnosed by GPs.

There are many methodological difficulties in comparing medical recording and its accuracy in different studies. The concepts 'documentation/detection rate' and 'recognition rate' lack clear definitions; one practical statement has been made by Van Hout [22], who proposes that the GP's detection rate of dementia should refer to the number of known patients with dementia in a GP's practice, and the recognition rate to the GPs diagnostic accuracy in consecutive patients. The retrospective design in studying medical documentation is prone to many methodological pitfalls, while the specified criteria used for dementia in different studies, and the unspecified criteria used in medical recording, vary. In addition to the difficulties of diagnosing dementia in primary care [5, 23, 24], there are also many factors that can influence the GP's documentation culture of dementia: nihilism about the medical treatment possibilities [1, 3, 5, 24, 25], lack of information about non-medical services [5, 24, 25], fear of stigmatising the patient [1, 23, 24, 26] and different expectations of caregivers [24–26]. However, a proper documentation of cognitive impairment and dementia is a prerequisite for giving information to all the members in a health care team; an extremely important issue of patient safety [27–29].

The passive approach to the diagnostic process of cognitive impairment and dementia seen in our study is remarkable in two ways: evaluations to find the reversible causes are insufficient and they are done at a late phase of cognitive impairment, more often when there is already obvious dementia. Of the patients with suspected memory impairment or dementia 51% had been tested for TSH, 20% for vitamin B12, 18% for serum calcium, and 78% for blood chemistries. Compared to the recommendations given internationally [6–8, 30] and nationally [31], these figures show that there really is a need to sharpen the diagnostic process in primary care. Our results could also encourage more GPs to use and produce guidelines for detecting and managing their patients with dementia.

Our findings suggest that in order to improve the detection of patients suffering from dementia GPs should pay special attention to those older people who are living at home, who are more depressed, and who have milder symptoms of cognitive and functional decline, as these patients are more often undetected. Also male sex was found to be associated with poorer detection in our study.

GPs could also do more consulting especially in the diagnostic process and management of patients over 75

years of age, as only one third was referred to a specialist. As the incidence of dementia and Alzheimer's disease is strongly age-related, and on the other hand the GPs accuracy of diagnosing Alzheimer's disease is only 50% [32], there is a discrepancy seen in the referral patterns in our study. All patients with dementia and those with advanced age should be entitled to an accurate diagnosis, as there are more specific treatment options available for dementing disorders such as Alzheimer's disease drug therapy.

Further education and training are the central issues in helping GPs to fulfill their role in the detection and management of dementia [5, 12, 23–25, 33], but there is also a growing need to strengthen and further develop cooperation between specialists and GPs. A study of German GPs showed that the chance of making a referral was higher among the GPs who experienced a readiness among specialist consultants to accept patients for the diagnosis of dementia [25]. Geriatricians, as well as neurologists and psychiatrists, could play an even more active role in this challenging collaboration of making the diagnostic process of dementia more active in primary health care.

In conclusion, our findings indicate that under documentation of dementia continues in primary health care, and the diagnostic evaluations performed to find reversible causes of dementia are insufficient. The need to develop the diagnostic processes for cognitive impairment in primary health care is obvious.

Key points

- Under-documentation of dementia continues in primary health care: less than half of the patients with dementia have this diagnosis in their medical records.
- Recommended evaluations to find reversible causes of dementia are not routinely performed in primary health care, and those evaluations that are done occur at a late phase of cognitive impairment.

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Conflicts of interest

None

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