ORIGINAL ARTICLE

A Swedish programme for dementia diagnostics in primary healthcare

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Abstract

Objective. To meet diagnostic needs of dementia, a new care programme was implemented in the county of Kalmar, Sweden. The objective of the study was to analyse whether the programme could identify and diagnose the estimated number of new cases. **Methods.** A long-term follow up study on all new patients referred to primary and specialist care between 1999 and 2005 for dementia evaluation. **Results.** Based on epidemiological data, 153 new cases per year were expected. Using the programme, an average of 127 cases was identified in primary healthcare and 22 at specialist level. Although the number of false-negative cases is not known, it may be concluded that most of the new cases with dementia were identified. The proportion of cases identified doubled after implementing the programme. The programme was implemented within an unchanged budget. **Conclusion.** The programme may be of value for diagnosis and management of demented patients in primary healthcare.

Key Words: Alzheimer's disease, dementia, dementia nurse, disease management, general practitioner, health economics, primary healthcare

The estimated number of people with dementia worldwide is 25–30 million, a number that is expected to increase considerably in forthcoming decades [1–3]. This is a great challenge with respect to identification, care, and treatment.

Even though most patients with cognitive impairment are already in contact with the Primary Healthcare Centres (PHC) the rate of under-diagnosis is substantial [4–6]. Therefore, education and training of PHC staff has been suggested as a method of improving the diagnostic process [7,8].

In the municipality of Kalmar, Sweden (60 000 inhabitants), a dementia programme was introduced stepwise, beginning in 1998 and involving the PHCs, specialists, and the municipal government [9]. The main focus was to identify early cases of dementia. In the initial phase of the programme, patients with dementia were identified with an inventory [10] and 538 patients were identified as having an established diagnosis ($n = 316$) or suspected dementia ($n = 222$) and those were further investigated. The estimated number of

To meet the increasing number of new patients with dementia, a new concept of disease management has been studied.

- This study presents a programme in primary healthcare settings with a focus on patients with cognitive impairment.
- The dementia management programme can detect the expected number of new cases of dementia

dementia cases (based on epidemiological and demographic data) was approximately 900. In addition, registered nurses from the PHCs were appointed dementia nurses (DNs), to whom new suspected cases were referred directly. Initially the DNs gathered the necessary information, enabling the general practitioner (GP) to establish a diagnosis according to the ICD [11]. In general, a basic diagnostic battery was used including medical and social history, cognitive tests [12,13], physical

examination, laboratory tests, ECG, and CT scan [14]. The DN's responsibility was to guide and support the patient and the family concerning the different aspects of dementia. The local social worker was introduced early in the process for care planning. Younger patients and complicated cases were referred to a specialist.

The objective of the study was to investigate whether the programme could identify and diagnose the expected number of new cases of dementia.

Materials and methods

The study was both retrospective and prospective, including several components: first, a comparison of the demographics of Kalmar compared with Sweden as a whole; second, an analysis of the dementia diagnostic investigations in Kalmar; third, an analysis of patients' contacts with the PHC. Finally, we analysed all known dementia patients in 2005 in the area.

The demographics of inhabitants aged 65 years and older in Kalmar between 2000 and 2005 were compared with Sweden as a whole. Furthermore, we compared the estimated incidence and prevalence of dementia in the municipality of Kalmar with Sweden as a whole [15]. Prevalence and incidence figures from literature were combined with age class (5 years) statistics [16,17].

Memory problems initiated entrance to the programme. All persons referred for a dementia investigation in PHC within the target area between 2000 and 2005 were examined according to the ICD 10 criteria [11]. The distribution of diagnoses in Kalmar was compared with that in the literature [18–20]. We also analysed the Mini Mental State Examination (MMSE) scores between 2000 and 2005. In addition, an analysis of ICD dementia diagnoses between 1995 and 2005 in the county council's central database [21] (hospital and PHC) was undertaken. All dementia diagnoses from local private physicians in the area were included. Further, an inventory of all known patients with a dementia diagnosis in the community in 2005 was performed (a cross-sectional study). Demographics such as gender, age, living conditions, and sources of referral were recorded. We hypothesized that the number of new cases with a dementia diagnosis that was identified by the programme would be similar to the estimated incidence in the area. From 2004 and onwards, a computerized database for the dementia programme was implemented. Thus, new diagnostic procedures could be performed for patients who were not diagnosed as demented or with possible dementia from 2004 onwards. In order to analyse the changes in resource use by patients of the PHCs,

all patient visits to physicians and nurses in PHC were recorded, with a special focus on visits by the elderly (70 years and older).

Data were recorded in SPSS® [22] and Microsoft Excel®. All variables were summarized using standard descriptive statistics. Comparisons between national and local data (gender, age, living conditions, diagnoses, frequency of demented patients, and costs) are based on population data and therefore not analysed for statistical significance. Student's t-test (95% CI) was used to analyse the MMSE score.

The study was approved by the ethics committee of Linköping university hospital, Dnr. 03-494.

Results

The demographics of the elderly in the municipality of Kalmar were basically similar to those for Sweden between 2000 and 2005 (about 17.3% 65+ in Kalmar; 17.5% in Sweden). There is a small difference of 1–2% in each age class, with a slightly higher proportion of women in Kalmar.

On average, 214 (range 160–257) patients were evaluated per year (Table I) of which 127 persons (range 113–157) obtained a dementia diagnosis at the PHC level. The diagnosis of "Unspecified dementia" decreased while mixed dementia increased. Additionally 22 patients per year were diagnosed at the local geriatric clinic. The number of patients diagnosed by specialists was stable throughout the period, and on the same level as GPs' numbers were, before introduction of the programme (Figure 1). A decrease occurred in 1997 when ICD9 was changed to ICD10. A small proportion were diagnosed by specialists in internal medicine and others (mainly private physicians). With introduction of the programme there was an increase of dementia diagnoses in the PHCs. There was a small imbalance of approximately 10% between the diagnoses in the central database and those in the PHCs.

At the start of the programme, the patients were most often referred by community social workers. However, after the introduction of the programme, an increasing number of evaluations were initiated directly by the GPs (Figure 2). No patients with a previously established dementia diagnosis re-entered the programme.

The mean MMSE score in 2000 for patients with a diagnosed dementia was 21.8 (95% CI ± 1.4) compared with 21.9 (95% CI ± 4.9) in 2005 ($n = 103$). In 2005, the mean score was 26.4 (95% CI ± 3.1) for suspected dementia ($n = 36$) and 27.0 (95% CI ± 3.2) without dementia diagnosis ($n = 36$). Of those not considered to be demented in 2004, one was later diagnosed with dementia in 2005 by a GP,

Table I. Registration from the PHC of patient referrals for dementia investigation during the introduction of the dementia programme in the PH organization in Kalmar community from 1999 to 2005.

	1999	2000	2001	2002	2003	2004	2005	Mean
Total	206	160	192	240	257	203	242	214.3
Proportion women (%)	68	64	63	62	48	61	51	59.6
Living alone (%)	–	–	64	51	48	61	51	54.9
Support from caregiver (%)	39.8	51.3	42.7	34.2	31.9	40.4	33.9	39.2
Mean age women	–	–	81	–	80	82	80	80.8
Mean age men	–	–	79	–	79	78	77	78.3
Diagnoses and referrals								
No dementia	56	33	32	40	53	49	82	49.3
Suspected dementia	28	14	42	43	59	33	44	37.6
Referrals to specialist	19	26	17	29	31	28	20	24.3
Final diagnoses (%)								
Alzheimer's disease	51	44	51	62	66	42	42	51.1
Vascular dementia	29	35	21	45	23	28	22	29.0
Frontotemporal dementia	3	3	5	3	5	1	1	3.0
Lewy body dementia	0	4	2	2	1	1	1	1.6
Mixed dementia	10	9	21	19	33	40	39	24.4
Unspecified dementia	29	18	18	26	17	9	11	18.3
Total with a dementia diagnosis from PH	122	113	118	157	145	121	116	127.4

Note: In some years (1999, 2000, and 2002) not all figures were collected.

and during 2005 and 2006, seven were further investigated by a specialist: four still had no dementia; one was diagnosed with Alzheimer's disease and one with vascular dementia.

Since the registration of patient visits to the PHC units started in 2000 and was reorganized in 2005, only the years 2000 to 2004 are presented in Figure 3. The number of elderly patients visiting the GPs (automatically registered) was unchanged (Figure 3) while there was a variation in the number of visits to the community nurse (self-registered) by elderly patients (Figure 3). In 2004 there were 26 full-time GPs and 54 community nurses working in the area.

Finally, 601 known dementia cases were identified in the inventory performed in 2005, corresponding to 67% of the estimated prevalence. In the 1997 inventory, 316 patients had a diagnosis of dementia (35%).

Discussion

The expected incidence and prevalence of dementia cases in Kalmar are approximately 153 and 889, respectively [15,16,23]. Thus, if it is assumed that only new dementia cases enter the programme and that there are no false-positive or false-negative

Figure 1. Registrations of diagnosed dementia patients from the County council (PHC =Primary Health Care centres, GR =geriatric clinic, IMED =internal medicine) and reporting by private physicians in Kalmar community from 1995 to 2005.

Note: "Others" includes patients from other departments, such as infectious diseases, surgery, and private physicians.

Figure 2. Referrals initiated by physician, community nurse etc. to the dementia programme (some of the patients had two or more referrals).

cases, the detection rate of dementia in PHC was 129/153 (84%). If the diagnosed patients in specialist care were included, however, approximately 100% were identified. Compared with the registers, the number of cases differs by only 10%. Since the number of diagnosed patients is similar to the expected incidence, we may assume that the programme is able to identify a major proportion of new cases. Olafsdottir et al. found that only 26% of patients with dementia and 9% of those with possible dementia had notifications of this in their case records [24]. A recent publication found that unawareness of dementia symptoms was as high as 70% among GPs [25]. In light of these findings, the results in Kalmar are acceptable and indicate a clear improvement in detecting dementia. Furthermore, as the programme continues, the dementia cases that are not diagnosed in one particular year may be identified in subsequent years. Other studies have found that when GPs are trained in the diagnosis of dementia, the detection rate has an acceptable accuracy [26] but, to our knowledge, no other study has so far confirmed this finding. The distribution of the different types of dementia in Kalmar correlates

with earlier studies [19,27]. The improvement in diagnosis as a result of the dementia programme is also reflected by a decrease in the proportion of “unspecified dementia”, which has largely been replaced by specific diagnoses.

Olafsdottir et al. showed that during the years preceding an established dementia diagnosis, the number of visits to the patient’s GP is very high [24]. At the time the programme was introduced in Kalmar there was an unchanged number of visits to the GPs but a variation in visits to the PHC nurses. Although we have no specific data on the number of visits for patients who have received a dementia diagnosis through the programme in Kalmar, it may be hypothesized that improved management of patients reduces the number of visits to nurses due to emergency events, changes in recording routines etc. The turnover of PHC staff in Kalmar has been fairly unchanged over the last few years. A possible explanation may be that the programme contributes to a more satisfactory working environment for the staff; this has to be further investigated.

Today the programme is well implemented in the PHCs in Kalmar. No extra funding was needed and the number of staff is unchanged. The basic premise of the programme is that all patients are entered when dementia is suspected. An alternative approach could be mass screening [28,29], however, most screening projects have been disappointing, since the screening methods are not sensitive or specific enough [8]. This is especially the case in PHC where the patients are highly heterogeneous. With a programme such as the one used in this study it may, however, be possible to detect the majority of new dementia cases without screening.

The present programme was not designed to analyse cost-effectiveness, since no comparison alternative was included from the beginning. Thus

Figure 3. Visits to general practitioners (GPs) and community nurses in Kalmar 2000–2004.

no statement of cost-effectiveness can be made. From a pragmatic cost-consequence viewpoint, there are indications that the programme improves the quality of dementia diagnoses (the outcome) without increasing the costs.

Some methodological problems are apparent. We found 153 cases per year, which was almost the number expected. This concordance might, however, be a coincidence. First, there is a risk that the programme misses patients with dementia if the possibility is not raised by the GP. Second, patients may be misclassified, as there was no confirmation of diagnoses by the use of a second opinion, which is common in epidemiological studies. Third, some cases may be diagnosed late and be prevalent rather than incident cases. However, the rather high MMSE scores support the hypothesis that mostly new cases are diagnosed. Fourth, at the beginning of the programme, prevalence estimates indicated that approximately 400 cases were not yet identified prior to introduction of the programme. During the study period 755 new patients were diagnosed. Thus, the doubling of known cases from 1997 (31%) to 2005 (67%) indicates diagnostic improvement. Finally, we have used the same geographical area as its own control. A comparison area could be an option, but such an approach is also problematic.

Conclusions

This study indicates that the dementia programme identified the expected number of new dementia patients in the area, and thereby represents a platform for appropriate management in terms of diagnostics, treatment, and psychosocial support. During the study period resource allocation did not increase.

Acknowledgements

The authors would like to thank all patients and PHC and staff in the Kalmar Municipality, and the Swedish Alzheimer Association for economic support.

References

- [1] Wimo A, Winblad B, Aguero-Torres H, von Strauss E. The magnitude of dementia occurrence in the world. *Alzheimer Dis Assoc Disord* 2003;17:63-7.
- [2] Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, et al. Global prevalence of dementia: A Delphi consensus study. *Lancet* 2005;366:2112-7.

- [3] Wimo A, Jönsson L, Winblad B. An estimate of the total worldwide societal costs of dementia in 2005. *Alzheimer's and Dementia* 2007;(in press).
- [4] Olafsdottir M, Foldevi M, Marcusson J. Dementia in primary care: Why the low detection rate? *Scand J Prim Health Care* 2001;19:194-8.
- [5] Reisberg B, Burns A, Brodaty H, Eastwood R, Rossor M, Sartorius N. Diagnosis of Alzheimer's disease. European Federation of Neurological Societies, the World Health Organization, and the World Psychiatric Association, *Alzheimer's Disease International*; 1997.
- [6] Valcour VG, Masaki KH, Curb JD, Blanchette PL. The detection of dementia in the primary care setting. *Arch Intern Med* 2000;160(19):2964-8.
- [7] Downs M, Turner S, Bryans M, Wilcock J, Keady J. Effectiveness of educational interventions in improving detection and management of dementia in primary care: Cluster randomised controlled study. *BMJ* 2006;332:692-6.
- [8] SBU. Dementia diseases. Stockholm: SBU-The Swedish Council on Technology Assessment in Health Care; 2006.
- [9] Strömquist J. Riktlinjer för demensutredning inom primärvården i Kalmar län/Vårdprogram demens i Kalmar län [Guidelines for dementia assessment in primary care in Kalmar County]. 2007 01-04-2006. Available at: http://www.ltkalmar.se/documents/Hälsa%20&%20Vård/Vårdguide%20A-Ö/vårdprogram/Demensutredning_06.pdf
- [10] Strömquist J, Johansson M. Dementia inventory in Kalmar community 1998. Kalmar; personal communication 2007.
- [11] World Health Organization. WHO international classifications, ICD 10. Geneva: WHO; 2007.
- [12] Folstein M, Anthony JC, Parhad I, Duffy B, Gruenberg EM. The meaning of cognitive impairment in the elderly. *J Am Geriatr Soc* 1985;33:228-35.
- [13] Harvan JR, Cotter V. An evaluation of dementia screening in the primary care setting. *J Am Acad Nurse Pract* 2006;18:351-60.
- [14] Waldemar G, Dubois B, Emre M, Georges J, McKeith IG, Rossor M, et al. Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline. *Eur J Neurol* 2007;14:e1-26.
- [15] Sjöberg M. På väg mot en god demensvård. Samhällets insatser för personer med demenssjukdomar och deras anhöriga [On the road to a favorable dementia care. Activities from the society to persons with dementia and their careers]. Stockholm. In: Welfare TNBoHa. ed. Fritzes; 2003.
- [16] Andreasen N, Blennow K, Sjödin C, Winblad B, Svardsudd K. Prevalence and incidence of clinically diagnosed memory impairments in a geographically defined general population in Sweden. The Pitea Dementia Project. *Neuroepidemiology* 1999;18:144-55.
- [17] Fratiglioni L, Forsell Y, Aguero Torres H, Winblad B. Severity of dementia and institutionalization in the elderly: Prevalence data from an urban area in Sweden. *Neuroepidemiology* 1994;13:79-88.
- [18] Aevansson O, Skoog I. A population-based study on the incidence of dementia disorders between 85 and 88 years of age. *Ann Intern Med* 1996;44:1455-60.
- [19] Snowden DA. Healthy aging and dementia: Findings from the Nun Study. 2003:450-4.
- [20] Olafsdottir M, Marcusson J, Skoog I. Mental disorders among elderly people in primary care: The Linköping study. *Acta Psychiatr Scand* 2001;104:12-8.

- [21] Kalmar Cc. Diagnose register. Kalmar: County Council of Kalmar; 2008.
- [22] SPSS. SPSS. Release 12.01. Release 12.01 ed. Chicago: SPSS Inc; 2003.
- [23] Fratiglioni L, Grut M, Forsell Y, Viitanen M, Grafstrom M, Holmen K, et al. Prevalence of Alzheimer's disease and other dementias in an elderly urban population: Relationship with age, sex, and education. *Neurology* 1991;41:1886–92.
- [24] Olafsdottir M, Skoog I, Marcusson J. Detection of dementia in primary care: The Linköping study. *Dement Geriatr Cogn Disord* 2000;11:223–9.
- [25] Jansen AP, van Hout HP, Nijpels G, van Marwijk HW, de Vet HC, Stalman WA. Yield of a new method to detect cognitive impairment in general practice. *Int J Geriatr Psychiatry* 2007;22.
- [26] Olafsdottir M, Marcusson J. Diagnosis of dementia at the primary care level. *Acta Neurol Scand Suppl* 1996; 165:58–62.
- [27] Lobo A, Launer LJ, Fratiglioni L, Andersen K, Di Carlo A, Breteler MM, et al. Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. *Neurologic Diseases in the Elderly Research Group. Neurology* 2000;54:S4–9.
- [28] Thibault JM, Steiner RW. Efficient identification of adults with depression and dementia. *Am Fam Physician* 2004;70: 1101–10.
- [29] Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: The first survey of Irish general practitioners. *Int J Geriatr Psychiatry* 2006;21:319–24.