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Dementia in primary care: why the low detection rate?

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***Objective* – The aim of the present study was to find reasons for the low detection rate of dementia in primary care. Another aim was to investigate the attitudes and knowledge on dementia among Swedish general practitioners (GPs).**
***Design* – Two-hundred-and-twenty-eight postal questionnaires were distributed to GPs in the county of Östergötland.**
***Setting* – Primary care in Sweden.**
***Main outcome measures* – The opinions of GPs on dementia management in primary care.**
***Results* – The response rate was 67%. GPs showed a good knowledge of dementia diseases but underestimated the occurrence of dementia. They presented a positive attitude towards managing patients with dementia and considered that existing drug therapy justified an active search for patients with dementia in primary care, but they believed the efficacy of the drugs to be limited. Assessing the social environment of patients and organising social support were regarded as the most difficult tasks in the management of demented patients.**
***Conclusion* – The study indicates that the main obstacles are a lack of resources and a sceptical attitude to the benefits of drug treatment. Co-operation between the community services, specialist clinics and the primary care team should be improved.**

***Key words:* dementia, family practice, family physicians, primary care, questionnaire, knowledge attitudes practice, disease management, detection rate.**

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Dementia has become a major health care problem because of its high prevalence (5–15%) in the population over the age of 70 (1–3). The economic burden on society is enormous (4).

The need for early diagnosis of dementia has further increased following the introduction of new anti-dementia drugs (5). The general practitioner (GP) and the primary care team have good opportunities for early detection (6) and play a central role both in diagnosing dementia and in its continuing medical care (7). Many studies have indicated that, in primary care, it is often difficult to diagnose dementia and to differentiate it from normal ageing, from other diseases and from drug side effects (8–12).

In 1993, the difficulties that Australian GPs had in diagnosing and managing dementia were surveyed (13). Some recommendations from this study were that cognitive check-ups for the elderly were desirable and that better co-ordination between specialist care and community services was needed.

In 1995–97 we performed a study with the aim of evaluating the prevalence of dementia in primary care settings. We found that dementia was common (20%) among elderly patients visiting a primary care centre (PCC). However, a remarkably low proportion (25%) of these was detected by the GP (12,14–16). We therefore planned a questionnaire study to evaluate possible explanations for this low detection rate. With a newly constructed questionnaire we investigated GPs' knowledge about dementia, as well as their attitudes and competence to manage patients with dementia.

MATERIAL AND METHODS

The study was conducted in the county of Östergötland, Sweden, which has about 400 000 inhabitants. Östergötland is representative of Sweden in terms of age distribution, economics, access to medical care and number of patients in nursing homes (17). A questionnaire was sent out in May 1998 to all GPs and GP registrars (16% of the group) working in this area (n = 228). Three reminder letters were sent. All participants worked in PCCs and each had medical responsibility for about 2000–2500 inhabitants. Every GP in Sweden has completed at least four and a half years of training before certification as a GP, including 4 months in geriatrics.

A team of GPs and geriatric specialists designed the questionnaire. Three independent GPs piloted it and commented on its content. It has three main parts (1. Background factors; 2. GPs' knowledge of dementia; 3. GPs' attitudes to treatment and management of patients with dementia) and there are three types of questions:

- Fixed-response alternatives.
- Statements where level of agreement is sought on a five-point Likert scale (strongly disagree/disagree/neither/agree/strongly agree). In the analysis, these were grouped into three categories (disagree/neutral/agree).
- Open comments.

RESULTS

Background factors

Of the 228 distributed questionnaires, 201 were returned (88%) and 153 (67%) were answered. The responders consisted of 63% men and 37% women (16% GP registrars) and the men had a significantly higher response rate ($p < 0.05$). The mean age of the responders was 47 years and 49 years for the non-responders ($p < 0.05$). The responders had been licensed 14 years and had worked as a GP for 10 years on average. The registrar's answers did not differ significantly. Fifty-two percent of the non-responders were women and 48% were men. Sixty-four percent of the non-responders reported that lack of time was the reason for their not completing the questionnaire.

The mean number of regular visits at the PCC reported by the GPs was 215 per month for each doctor, and the most common proportion of elderly (> 65 years) was 41–60%.

Knowledge of dementia

The majority of GPs regarded Alzheimer's disease, vascular and mixed dementia as the three most common forms of dementia. The symptoms indicating early dementia most commonly mentioned by GPs were: memory disturbances (ranked first, reported by 87% of the GPs); changes of personality (50%); followed by psychiatric symptoms (47%); cognitive disturbances (45%); delirium (30%); changes in activities of daily living (22%) and somatic symptoms (6%).

The GPs' estimates of the occurrence of dementia, depression, hypertension, diabetes and heart disease among their elderly patients are shown in Fig. 1. Eighty-two percent estimated the prevalence of dementia to be less than 10% and dementia was regarded as the least common of the provided chronic diseases.

Fewer than 8% of the GPs regarded dementia as a consequence of normal ageing. Twenty percent of the GPs agreed that their own knowledge and experience was adequate to detect patients with dementia, to identify types of dementia and to make a differential diagnosis. Seventy-one percent wanted to increase their knowledge on dementia.

Current management

Fifty-two percent of the GPs estimated that they managed 80–100% of the patients on their own, i.e. referred less than 20% to a specialist. Furthermore, the GPs estimated the likelihood of certain groups initiating an investigation of memory disturbances in the PCC. PCC personnel ranked highest (67% of GPs agreed), GPs themselves (46%), relatives (44%), social workers (29%) and patients themselves (16%).

The inclination of GPs to discuss different medical topics with their elderly patients was as follows: general well-being (90% of GPs agreed that they willingly did so), blood pressure (77%), sleeping disorders (73%), hearing (58%), cognitive disturbances (57%), weight (52%), urinary incontinence (50%), cholesterol (32%) and holding a driving licence (12%).

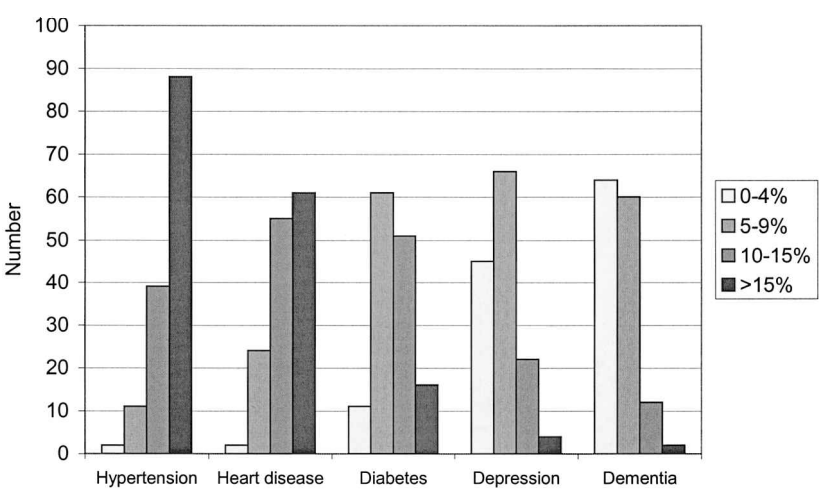

Fig. 1. GPs' estimation of the occurrence of common diseases among their elderly patients attending the primary care centre (PCC). Number of GPs responding to the fixed alternatives for each disease.

Table I. GPs' assessment of factors that influence their decision on whether or not to give anti-dementia treatment. Five different reasons for prescribing and six reasons for not prescribing are given. The GPs were able to mark two answers. The percentages are the proportions of GPs who agreed with the statement

Reasons for drug treatment with cognitive enhancers	%
The treatment can affect/influence the course of the disease	66
The patient is in the early stages of the disease	64
The treatment can relieve the symptoms of the disease	49
The patient's family requests therapy	13
It may be worth trying some treatment against such a difficult disease	12
Reasons for NOT giving drug treatment	
The patient is in the late stages of the disease	73
The drug has too small an (anti-dementia) effect.	53
The patient or relatives do not want any treatment of the dementia	39
The drug has too many side effects	26
The drug is too expensive	8
The drug lengthens life that is not worth living	1

According to 93% of the GPs, the problem most likely to trigger a dementia investigation is relatives' complaints about a patient's memory loss. The second most likely is the patient's complaint of memory disturbance (90%); third, the patient's seeming confused during the consultation (88%).

Fifty-seven percent of the GPs said they would always, or often, discuss the diagnosis and consequences of the dementia with the patient and 52% with a relative, in their next visit after diagnosing dementia.

Attitudes regarding drug therapy

More than half (55%) of the doctors agreed that existing drug therapy would justify an active search in primary care for patients with suspected dementia. Their reasons for treating or not treating with anti-dementia drugs are given in Table I. In free comments, some GPs suggested that drug treatment could enable patients to remain independent for longer. Many GPs wanted to await a consensus before starting to prescribe anti-dementia drugs.

Fewer than half of the GPs (43%) were definitely satisfied with the co-operation with the specialist clinic and 24% were definitely satisfied with the co-operation with community services when managing dementia patients.

Mapping and organising social support were the most difficult tasks in the management of patients with dementia (agreed by 56% of the GPs), followed by initiating specific treatment (42%) and ensuring early detection (39%). In free comments, some GPs found difficulty when informing the patient about their medical condition and explaining their cognitive deficit and their need for a specific investigation. Another comment was that some patients with behavioural problems were difficult to manage.

The predominating factor that could facilitate the care of dementia was having fewer patients and thereby more time for each patient, 69% of the GPs agreed with this statement. Forty-three percent agreed that a specially trained dementia co-ordinator employed at the PCC would facilitate and 15% agreed to have one GP responsible for demented patients in PCC. Some GPs expressed the importance of educating and informing the public about dementia.

DISCUSSION

Although we do not know the opinion of the non-responders, we have gained insight to the knowledge, attitudes and ideas of the majority of GPs. Most non-responders claimed that lack of time was the reason for not responding. We do not know if this also reflects a lack of time in the clinical work, which could have a bearing on the results in our survey. Despite the response rate to postal surveys consistently falling among GPs (18), researchers are making increasing use of questionnaire surveys to assess GPs views and attitudes (19).

Most of the responders were experienced and had a high proportion of elderly in their practice – confirmed in our previous study, where 40% of attendees were elderly (6,14).

The GPs demonstrated a good knowledge of the clinical features of dementia, but, nevertheless, a majority regarded their knowledge as insufficient and asked for more education in this field. This was also verified in the Australian survey in which GPs asked for clear assessment procedures and an easy-to-use screening instrument (13).

The GPs in our study underestimated the occurrence of dementia, indicating many undetected patients, which is in line with our previous study (14).

The majority of the GPs reported that they handled most of the patients with suspected dementia themselves. They stated that, along with PCC personnel, they were the ones most likely to initiate a dementia assessment, which emphasises primary care's responsibility for early detection.

The GPs stated that existing drug therapy justified the active search for patients with dementia in primary care. However, 53% of the GPs definitely viewed these drugs as having a small anti-dementia effect and ranked this as the second reason for not

prescribing these drugs to patients. Whether to give anti-dementia treatment or not depended chiefly on the stage of the patient's dementia and on the likelihood of the treatment influencing the course of the dementia. The high correlation between prescribing a drug and making a diagnosis in medical records has been described in primary care (14). This scepticism about anti-dementia drugs may also explain the low detection rate of dementia.

Only half of the doctors said they would discuss the diagnosis and prognosis of dementia with the patient or relative on their next visit after the diagnosis of dementia. This was supported by a British study on this topic, where 39% of GPs would always or often tell patients their diagnosis of dementia, compared with 95% in cases of terminal cancer (20). Fifty-seven percent of GPs reported that they readily discuss cognitive disturbances with elderly patients, but only 12% discuss the patient's holding of a driving licence, which may suggest that Swedish GPs do not readily discuss cognitive disturbance.

GPs saw neither the diagnostic procedure nor early detection as the most difficult part of managing dementia. The most difficult parts proved to be assessment of the social circumstances and organising social support. At this point the co-operation between primary care and the community services is very important, but only 24% of the GPs were definitely satisfied with this co-operation.

Sixty-nine percent of the GPs thought "more time for each patient" was the single most important factor for improving dementia management. GPs also found it valuable to have a dementia co-ordinator (a specially trained social worker or nurse) employed at the PCC. Whether the GPs find early detection of dementia beneficial or not is partly unanswered in this survey. The benefits are still debatable (21) and likely to influence some GPs willingness to look for the disease.

LIMITATIONS

In this study we investigated the attitudes and thoughts of respondents, but we do not know how closely their responses depict their real work. Most of the questions were closed, and this may have biased the answers. However, having the option of open answers lessened the risk of missing important views. The main limitation is that we do not know whether the non-responders differ significantly from the responders; it could be assumed that the GPs who answered were those most interested. Nevertheless, their opinions provide useful insight into existing obstacles for detecting and managing dementia in primary care.

CONCLUSION

GPs underestimated the prevalence of dementia among elderly patients in primary care. However, this alone is unlikely to explain the low detection rate. The two main obstacles to better detection of dementia revealed in this study are, first, a sceptical attitude to drug treatment and, second, experience of poor co-operation with the community services.

Despite this, we found that GPs were willing to undertake the management of patients with dementia. We are convinced that the most important role of GPs is in detecting patients with dementia and making a medical assessment. Focusing on this, and ensuring that someone else has the co-ordinating function, can improve the early detection of patients with dementia.

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