Dementia in primary care: the first survey of Irish general practitioners

Suzanne Cahill1*, Maeve Clark1, Cathal Walsh2, Henry O’Connell3 and Brian Lawlor4

1Dementia Services Information and Development Centre and Trinity College Dublin, Ireland
2Department of Statistics, Trinity College Dublin, Ireland
3Mercer’s Institute for Research on Ageing, Ireland
4St. James’s Hospital, Dublin Trinity College Dublin, Ireland

SUMMARY
Objective To investigate General Practitioners’ (GPs) attitudes and practices in relation to screening, diagnosing, and disclosing a dementia diagnosis to patients.
Design National postal survey.
Participants A random sample of 600 GPs from a national database of 2400.
Results Of the 600 GPs surveyed, 60% returned questionnaires of which 50% (300) were useable. GPs reported diagnosing on average four new cases of dementia annually. A multivariate analysis revealed that females diagnosed significantly fewer cases annually (t = 5.532, df = 289, p < 0.001). A large majority of GPs reported performing thyroid function tests (77%), B12 (75%) and Folic acid tests (75%) to rule out reversible causes of cognitive impairment. The most reliable signs and symptoms of dementia identified were memory problems (58%). Main barriers to diagnosis were difficulty differentiating normal ageing from symptoms of dementia (31%), lack of confidence (30%) and the impact of the diagnosis on the patient (28%). GPs’ age (χ² = 14.592, df = 3, p < 0.005) and gender (χ² = 11.436, df = 3, p < 0.01) were significantly associated with barriers to diagnosis. Only 19% claimed they often or always disclosed a diagnosis to a patient. Over one-third of GPs (38%) reported that the key factor influencing their disclosure patterns was their perceptions of the patient’s level of comprehension. Most GPs (90%) had never undergone any dementia specific training and most (83%) expressed a desire for this.
Conclusions GPs experience difficulty diagnosing and disclosing a diagnosis of dementia to patients. To improve dementia care in Ireland, there is an urgent need to develop an active and more systematic approach to GP training in dementia care. Copyright © 2006 John Wiley & Sons, Ltd.

key words — dementia; diagnosis; disclosure; GPs; barriers

INTRODUCTION
An early diagnosis of dementia is today more relevant than ever before, due to the increasing numbers of therapies available to treat Alzheimer’s disease and other related dementias (Geldmacher et al., 2003) and a growing awareness about the benefits of early interventions (Leifer, 2003; Peterson et al., 2005). GPs are in a strategic position to recognise dementia and by virtue of the large numbers of patients presenting to primary care, to play a key role in its diagnosis. Yet, there remains a dearth of evidence available about levels of detection and diagnosis of dementia in primary care. The largest UK survey was conducted by the Audit Commission for its 2000 and 2002 reports (Forget Me Not), but the results from these works were not generalisable since they were based on large numbers of GPs in select areas (Milne et al., 2000). Most other studies have been small-scale and regional, using non-random samples (Fortinsky et al., 1995; Downs et al., 2002; Bamford et al., 2004). One exception has been a Norwegian...
study (Braekhus and Engedal, 2002). However, the latter did not examine the frequency of dementia diagnosis in primary care, nor did it investigate reasons for non-disclosure. The recently reported work of the INTERDEM group (Vernooij-Dassen et al., 2005) has helped shed light on the topic of barriers to the timely recognition of dementia across eight European countries but this work was based on Focus Groups, held with a panel of multi-disciplinary experts, the majority of whom were not GPs. The authors themselves have acknowledged this limitation. There is also some evidence in the literature suggesting that GPs may not accurately estimate the prevalence of dementia in their caseloads. A recent UK based study reported that GPs’ poor understanding of the epidemiology of dementia leads to an over-estimation of cases in their practices (Turner et al., 2004).

AIMS

We assessed the numbers of new cases of dementia diagnosed by Irish GPs annually and the frequency with which they disclose a diagnosis to their patients. We sought to determine what factors might influence GPs’: (i) diagnostic practices and (ii) their disclosure patterns to patients.

METHOD

We carried out a survey of Irish GPs whose names were listed on the Irish College of General Practitioners (ICGP) database. An anonymous questionnaire, pre-tested with Geriatricians, was posted out in November 2003. A reminder letter and a further questionnaire were sent one and two months later.

Sample

Our sampling frame consisted of all GPs registered with the ICGP. We randomly selected one in four GPs from the ICGP database (600 out of 2400). The sample was representative of ICGP general practitioners in relation to gender and Health Board.

Questionnaire

Two questions, one open-ended and the other using a four-point Likert scale were asked about the frequency of diagnosis. Pre-coded questions collected data on diagnostic work-up. Barriers to diagnosis were drawn from the literature and on our own experience. Six response categories were used namely: (i) confidence in making a diagnosis; (ii) impact of diagnosis on patient; (iii) difficulty differentiating normal ageing from symptoms of dementia; (iv) difficulty conveying bad news; (v) embarrassment and (vi) other. To collect data on frequency of disclosure, a pre-coded question offering response categories ranging from never to always was asked. Barriers to disclosure were also drawn from the literature. A pre-coded question was designed with 11 response categories.

Statistical analysis

We computed means, ranges and standard deviations for continuous variables and distributions for frequencies of categorical variables using SPSS 11 and DataDesk 6.1 packages. To examine factors determining GPs diagnostic practices, we did a multivariate analysis adjusting for confounding variables including GPs’ ages, training background and the age distribution of patients.

RESULTS

A response rate of 60% (359/600) was achieved. However, 59 questionnaires were invalid (due to incomplete responses, ineligibility for the study, or GPs being retired or no longer in practice), leaving a total of 300 useable questionnaires. Analysis showed that the demographic profile of the GPs who participated matched that of the non-responders with respect to gender ($\chi^2 = 0.9$, df = 1, $p < 0.5$).

GP and Practice Profile (Table 1)

The mean age of all respondents was 45 years (median = 45; SD, 10.8). Female GPs whose mean age was 39 years (SD, 8) were significantly younger than their male counterparts (mean = 49, SD, 11). The proportion of female GPs in the sample was 39%, similar to that found in the national population of GPs. Vocational training was held by 45% of GPs, self-structured by 27% and the remainder had a combination of training. The majority (90%) had no dementia specific training. However, when asked, a large majority (83%) expressed a desire for this. Most GPs (94%) worked in mixed practices (seeing both private and public patients).
Clinical practice (Table 2)

Mean number of new cases of dementia diagnosed annually was 4 (range = 0–20; SD, 3.3). The most reliable signs and symptoms of dementia identified by GPs were memory problems (58%), impaired activities of daily living (14%) and disturbances in higher cortical functioning (11%). A large majority reported they performed thyroid function (77%), B12 (75%) and Folic acid tests (75%) to outrule reversible causes of cognitive impairment when dementia was suspected. Only 40% requested CAT and 12% MRI brain scans for diagnostic work up. Over two-thirds (69%) claimed they regularly or sometimes diagnosed dementia. Analysis revealed that females diagnosed significantly fewer cases annually ($t = -3.250, df = 213, p < 0.001$) and those in practice for over ten years diagnosed significantly more ($t = -3.463, df = 288, p < 0.001$). A multivariate analysis which adjusted for the available confounding variables namely, the age profile of GPs, their training background, and the age distribution of patients, showed a statistically significant relationship between gender and number of new cases of dementia diagnosed annually ($p < 0.001$) with female GPs diagnosing significantly fewer cases per year.

Barriers to diagnosis

Main barriers to diagnosis identified by GPs included difficulty differentiating normal ageing from symptoms of dementia (31%), lack of confidence (30%), and concerns about the impact of the diagnosis on the patient (28%). Neither practice type (single vs group), location (urban vs rural), or number of years in practice were associated with these barriers. Instead analysis revealed age ($\chi^2 = 14.592, df = 3, p < 0.005$) and gender ($\chi^2 = 11.436, df = 3, p < 0.01$) differences, with both females and younger GPs more likely to lack confidence and both males and older GPs more likely to have difficulty differentiating normal ageing from dementia symptoms.

Disclosure (Figure 1)

Only 19% of GPs reported they often or always disclosed a diagnosis to a patient and 41% claimed they never or rarely told. Analysis showed that neither gender ($\chi^2 = 2.15, df = 2, p = 0.34$), nor diagnostic

---

Table 1. GP and practice profile

<table>
<thead>
<tr>
<th>Age</th>
<th>Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age of GP</td>
<td>45 Vocational 45%</td>
</tr>
<tr>
<td>Range</td>
<td>27–88 Self-Structured 27%</td>
</tr>
<tr>
<td>Gender</td>
<td>Combined 28%</td>
</tr>
<tr>
<td>Male</td>
<td>61% Practice Type Group 63%</td>
</tr>
<tr>
<td>Female</td>
<td>39% Single 27%</td>
</tr>
<tr>
<td>Domicile</td>
<td>Practice Type Mixed Practices 94%</td>
</tr>
<tr>
<td>Rural</td>
<td>17% GMS only 3%</td>
</tr>
<tr>
<td>Combined</td>
<td>4% Private Practices 3%</td>
</tr>
</tbody>
</table>

Table 2. GP Diagnostic frequency and socio-demographic profile

<table>
<thead>
<tr>
<th>Socio-demographic variables</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4.6</td>
<td>3.7</td>
</tr>
<tr>
<td>Female</td>
<td>2.5</td>
<td>2.0</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Structured Training</td>
<td>2.9</td>
<td>0.6</td>
</tr>
<tr>
<td>Vocational Training</td>
<td>2.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Years in Practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 10 years</td>
<td>2.8</td>
<td>1.9</td>
</tr>
<tr>
<td>Ten years or more</td>
<td>4.2</td>
<td>3.7</td>
</tr>
</tbody>
</table>
frequency ($\chi^2 = 9.5, df = 6, p = 0.15$) were significant factors, in determining disclosure to a patient. Out of the 11 response categories provided, GPs’ perceptions of their patient’s ability to comprehend the diagnostic information emerged as the main factor determining the disclosure or non-disclosure of dementia to a patient with 38% selecting this response category.

DISCUSSION

Our main findings were that GPs reported they diagnosed an average of four new cases of dementia annually; most could identify obstacles to diagnosis, and the majority expressed a desire for specialist training. Only 40% requested CAT and 12% MRI brain scans during diagnostic work-up. This may reflect difficulties in accessing such investigations particularly in rural Ireland where local access to MRI scanning is non-existent. Only 6% claimed they always disclosed the news of a diagnosis to their patient and 13% stated they often did.

The low disclosure rates found in this study, contrast sharply with those reported elsewhere. A recent Norwegian national survey (Braekhus and Engedal, 2002) showed that two-thirds of GPs often or always disclosed the diagnosis of dementia to a patient and only 6% never or rarely told. Our findings are also discordant with results from a British survey (Vassilas and Donaldson, 1998), which showed that 40% of GPs often or always disclosed a diagnosis to a patient. Some possible explanations behind the low disclosure rates in Ireland may include: (i) the late presentation of dementia in Ireland because of stigma; (ii) the absence of any GP specialist training in dementia and (iii) therapeutic nihilism. An Irish study published several years ago concluded that whilst the majority of primary caregivers would welcome information about their diagnosis were they to acquire a dementia, most would not wish their relative to be informed (Maguire et al., 1996). However, this study was undertaken prior to the advent of anti-dementia drugs and drew on a sample of primary caregivers, not persons with dementia. Today an early disclosure of diagnosis seems to be what people with dementia want and what younger professionals favour (Jha et al., 2001; Sullivan and O’Connor, 2001; Iliffe and Manthorpe, 2004).

Findings relating to gender differences surrounding diagnostic practices are also discordant from those recently reported (Turner et al., 2004). One explanation behind why females in this sample diagnosed fewer cases may be that women are more likely to be employed in part-time practices and consequently may be examining and diagnosing fewer patients. They are also more likely to be involved in women’s health issues, which may result in their seeing a younger profile of patient. A limitation of this study’s design is that no information was collected on the nature of GPs’ employment arrangements such as the number of daily hours worked or numbers of patients seen. A second explanation may be that gender and age are closely associated variables as females in this sample were younger than their male counterparts. Future studies now need to address this important area, particularly as recent reports suggest that more female students in Ireland are entering the GP programme.

Other limitations to the study include the fact that data are based on GPs’ perceptions of their diagnostic behaviour and not on more objective measures. This may call into question the validity of some of the data since findings may not reflect true practice. However, alternative approaches such as observational studies are not feasible in General Practice and caregiver or patient interviews are unlikely to yield reliable data. There is also limited routinely collected information in Ireland on GPs diagnostic activity, so we have no national data-set, which contains information on the actual numbers of cases of dementia diagnosed by GPs annually and hence we have no body of information with which to compare our results.

Non-response is an important source of bias in survey research and several studies have testified that GPs are a particularly difficult group to survey (Kaner et al., 1998; Thomson et al., 2004). It remains unclear what constitutes a satisfactory response to GP surveys, but there is growing evidence that response rates have been falling consistently over recent years. A recent Cambridge based Internet survey of GPs yielded a response rate of 52% but this was after five emails were circulated (Braithwaite et al., 2003). In contrast the uptake to this survey was good, with questionnaires answered comprehensively and additional information volunteered. In keeping with other studies, we suspect that offering GPs an incentive for an early return may have boosted our response rate. We also suspect that like other European countries, there is a growing interest among Irish GPs in the topic of dementia as a result of an ageing population and public education programmes.

Despite the high response rate (60%) achieved in this study, the issue of some level of response bias cannot be outruled. Whilst we are aware that our respondents did not differ from the non-responders.
in relation to gender, we have no knowledge of how the two groups may have differed regarding other critical variables such as years in practice, age of GPs and group vs single practices. This issue needs to be kept in mind when interpreting the results.

CONCLUSION

This study provides new insights into the difficulties Irish GPs experience when a patient presents with a suspected dementia. In particular, it has yielded a wealth of information about GPs’ attitudes to diagnosing and sharing information about dementia to a patient. Whilst in general, the GP’s in this sample report they regularly diagnosed dementia, many it seems may have over-estimated the incidence of dementia (Turner et al., 2004) since the numbers of new cases they purported to diagnose annually far exceeds EURODEM estimated incidence figures (O’Shea and O’Reilly, 1999).

In terms of disclosure patterns, the data showed an overall reluctance on the part of GPs to share the news of a dementia with a patient. Reasons include their perceptions of a patient’s ability to understand information about the diagnosis (due presumably to late presentation) and the impact the disclosure might have on the individual because of the associated stigma. GPs’ own attitudes to dementia and the stigma associated with its diagnosis, although not overtly investigated in this study is also likely to be an over-arching factor impacting on GP behaviour (Vernooij-Dassen et al., 2005). Whilst GPs behaviour is said to be changing with upskilling occurring spontaneously in other areas of medical practice such as in heart disease, hypertension, asthma, diabetes and depression, why are similar changes not occurring spontaneously in the area of dementia? It may well be that the stigma of dementia is one reason why doctors are not learning more rapidly ‘on the job’ about how to best deal with and manage the issue of dementia in the community.

The work reported here is unique, insofar as within Europe, no other nationwide survey has been undertaken, addressing the topic of GPs’ diagnostic practices and disclosure patterns regarding dementia. This is despite the excellent recent European work of the INTERDEM Group where obstacles and facilitators to dementia diagnosis were investigated and where it was noted that the stigma associated with dementia by professionals appeared to be the most powerful obstacle to a timely diagnosis (Vernooij-Dassen et al., 2005). Regrettably this means that no similar European data-set exists with which to compare our results.

Our findings demonstrate an unequivocal desire on the part of GPs for upskilling in the area of dementia and recognition that this has been a deficit in their training. These findings have important implications for educators and for those involved in the design and delivery of GP post-graduate training programmes. Whilst it is noted that the best approach to acquiring education about dementia for effective primary care is not yet known (Iliffe et al., 2002), we need to listen to what GP’s themselves have to say about the topic. Educational programmes need to be designed to assist GPs to differentiate symptoms of dementia from those of mild cognitive impairment, and age-related memory problems. Courses need to be developed which provide practical support to GPs about strategies for communicating news of a chronic and stigmatizing illness to patients and family caregivers. Given the consensus on barriers to the timely recognition of dementia in the community, educational strategies need to be multi-pronged and need to include problem-based learning approaches along with e-learning and CD-Rom modalities.

Younger GPs, those new to practice, and females, may need particular support since as our findings suggest, these are sub-groups who appear less confident and tend to diagnose fewer cases. Counselling programmes need to be developed aimed at educating patients newly diagnosed and their family members about coping strategies and about maintaining independence. Other members of the primary care team such as practice nurses and community nurses also have a critical role to play in this area, in terms of supporting families and people newly diagnosed. Educational programmes tailored to their particular professional and learning deficits, now need to be designed. Hospital-based Social Workers also need to be upskilled in dementia care and organisations like the Dementia Services Information and Development Centre already active in the area of training health service professionals in Ireland, needs to expand its remit and develop more online, e-based learning. For individuals and their caregivers, telephone help-lines such as those provided by Alzheimer’s Societies, should be extended around the clock. GPs might feel less nihilistic about providing a diagnosis of dementia, if these types of support services were available.

Finally, it needs to be acknowledged that this patient group is likely to suffer multiple pathologies (including cancers, coronary diseases, arthritis and depression), which may overshadow and indeed in some cases mask the symptoms of dementia. Such conditions (whether rightly or wrongly) may be judged to

Copyright © 2006 John Wiley & Sons, Ltd.
KEY POINTS

- Irish GPs experience difficulties diagnosing dementia.
- The rate of disclosure of dementia by Irish GPs is low compared with disclosure patterns in other countries.
- There is an urgent need to develop active and more systematic approaches to GP training and dementia care.
- There is a need to develop accurate records in Ireland on GPs diagnostic activities including the rate at which dementia is being diagnosed annually.

take a higher priority over the investigation of symptoms of a possible dementia and may lead GPs to decide not to disclose a diagnosis. In the complexities of disentangling dementia from the signs and symptoms of normal ageing and identifying dementia subtypes, this issue also needs to be kept in mind.

In conclusion, the scale of the study, the high response rate achieved and the amount of qualitative data generated (as yet unpublished) has provided a rich and critical source of information to help guide future service development in the context of dementia and primary care in Ireland. Primary care is the bedrock of a national health service, and improvements in dementia care.

REFERENCES


