

The attitudes and practices of general practitioners regarding dementia diagnosis in Ireland

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SUMMARY

Background The diagnosis of dementia poses difficulties for general practitioners (GPs) particularly when access to specialist diagnostic services is delayed. Ireland is soon to witness an increase in numbers of people presenting with dementia, yet little is known about the service needs of GPs when attempting to diagnose dementia.

Objectives To detail the service needs of GPs, especially their training needs, access to diagnostic resources such as CT and MRI brain scans and access to specialist services such as Old Age Psychiatry (OAP), Geriatric Medicine (GM) and Neuropsychology (NP).

Methods The paper is based on survey data collected from a sample of GPs ($n = 300$) registered with the Irish College of General Practitioners (ICGP) and on qualitative data collected from a Focus Group ($n = 7$).

Results GPs were more likely to blame themselves than either the health care system, their patients or family members for the late presentation of dementia in primary care. Stigma was a major obstacle preventing GPs from being more proactive in this area. Rural GPs felt geographically disadvantaged accessing diagnostic services and both rural and urban GPs experienced considerable time delays accessing specialist diagnostic services.

Conclusions Findings provide compelling evidence that training and access to diagnostic services are only two of several different structural and ideological obstacles that GPs encounter when attempting to diagnose dementia. Future educational supports for GPs need to be developed which concentrate on these areas. Copyright © 2008 John Wiley & Sons, Ltd.

KEY WORDS—dementia; General Practitioners (GPs); diagnosis; training

INTRODUCTION

By European standards, Ireland remains a youthful country (O'Neill and O'Keefe, 2003). Today, older people represent approximately 11.5% of the Irish population, a figure which contrasts sharply with a European average of 15% (O'Neill and O'Keefe, 2003). Despite this, the number of older Irish people is expected to increase, with those over 65 representing 14% of our population by 2011 (Fahey, 1995). Like Europe, population ageing in Ireland will mean a rise in disability and an increase in demand for services. Already there is concern that there are insufficient GPs

to meet the increasing needs of ageing populations (Fortinsky *et al.*, 1995; Iliffe *et al.*, 2004; Martin, 2004; Calnan, 2005). There is also concern that dementia, an age related illness, challenges GPs, often the first point of contact for family members. Given, there are 38,000 people with dementia in Ireland (O'Shea, 2007) with numbers likely to reach 52,000 by 2026 (O'Shea and O'Reilly, 1999) such concerns are justified. A booming Irish economy also means that reliance on informal carers to provide care services may no longer be possible. Such a phenomenon will place further demands on GPs who are the gatekeepers to service provision for the elderly.

In the past, the urgency to diagnose dementia did not exist; the belief being that supportive therapy was the only available option (Juby *et al.*, 2002). With the advent of anti-dementia drugs however, there is

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evidence that early diagnosis and timely interventions are more beneficial than ever (De Lepeleire and Heyrman, 1999; Leifer, 2003; Woods *et al.*, 2003). Despite this, therapeutic nihilism prevails (Woods *et al.*, 2003; Downs, 2005; Iliffe *et al.*, 2005; Peterson *et al.*, 2005; Vernooij-Dassen *et al.*, 2005) and it has been noted that there is still a need to convince GPs that dementia is a condition for which much can be done (De Lepeleire and Heyrman, 1999). Gaining an understanding of GPs experiences when attempting to diagnose dementia in primary care is critical to service planning and development. This study therefore set out to examine five key research questions, namely: (i) who is responsible for the late presentation of dementia in Ireland?; (ii) how long must GPs wait to access Geriatric (GM), Old Age Psychiatry (OAP) and Neuropsychological (NP) services?; (iii) what are the main barriers they experience attempting to diagnose dementia?; (iv) might financial incentives improve detection rates; and (v) what type of specific training and diagnostic guidelines might assist rural based GPs regarding dementia?

Diverse barriers to early diagnosis in primary care have already been noted. These include stigma (Brodaty *et al.*, 1994; Morgan *et al.*, 2002; Iliffe *et al.*, 2005; Vernooij-Dassen *et al.*, 2005), difficulty in differentiating normal ageing from dementia (Boise *et al.*, 1999; Iliffe *et al.*, 2003), the paucity of specialist diagnostic services, especially in rural areas (Freyne, 2001; Shores *et al.*, 2004), and GPs lack of confidence or training (Turner *et al.*, 2004). As there is no definitive test for dementia, GPs must investigate several possibilities and may not always have the time or expertise for this (Brodaty *et al.*, 1994; Iliffe *et al.*, 2003). Earlier work has shown how GPs would be more proactive if a 5 min screening tool was available (Bush *et al.*, 1997). In a recent study decision-support software and practice-based workshops proved effective in improving GPs dementia detection rates, but not in improving compliance with best practice principles (Downs *et al.*, 2006). Financial incentives may also assist GPs to better manage chronic illnesses including dementia (Downs *et al.*, 2006).

METHODS

Research design

The ICGP database of 2400 Irish registered GPs acted as a sampling frame from which to draw a random sample of 600. The design of this research and how the sample was drawn have been detailed earlier (see Cahill *et al.*, 2006).

Survey instrument

Details of the 22-item questionnaire are reported elsewhere (Cahill *et al.*, 2006). The questions relating to this paper include an open ended one on reasons behind late presentation of dementia in primary care and two other questions about GP's service needs and service usage.

Statistical analyses were conducted using SPSS for Windows version 11 and DataDesk version 6.1.

Focus group

Preliminary analysis of survey data raised questions about rural GPs which the researchers considered would be best addressed through qualitative methods. A focus group rather than in-depth interviews was considered the preferred method since it was felt the required information could be gathered more efficiently and expediently. Convenience sampling was used. For pragmatic reasons, focus group size was kept small. A second focus group with urban GPs was considered unnecessary since no urban specific queries arose in the survey data. Following perusal of survey data, a prompt guide (see Appendix 1) for discussion was designed to ensure topic coverage. The session was audio-taped and facilitated by two dementia experts.

Focus group data was transcribed verbatim and coded thematically. The facilitators, developed agreed codes, categories, themes and recorded the location of each code. This assisted in the appropriate openness and utility of the coding, producing a systematic method of data analysis and storage. Where differences of opinion in coding emerged, transcripts were cross checked to ensure inter-rater reliability (Rubin and Babbie, 1989). Iterative processes ensured rigour in both data collection and analysis (Krefting, 1991).

RESULTS

For clarity of presentation, survey and focus group findings are presented separately.

Survey findings

Response rate. Sixty percent of GPs responded (359/600). A total of 300 GPs were included in the study. Incomplete and ineligible questionnaires ($n=59$) were discarded. The majority (79%) reported being in urban practices.¹

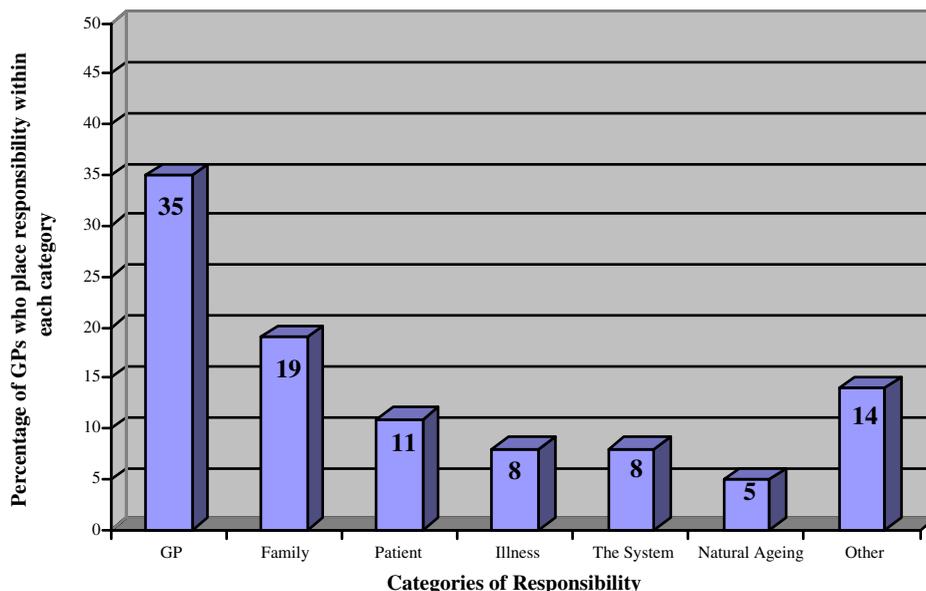


Figure 1. GP's perceptions about responsibility for the late presentation of dementia ($n = 284$).

Late presentation of dementia: who is responsible?

An open-ended question was asked regarding why patients with dementia present late² for diagnosis. Analysis (see Figure 1) revealed how more than one-third (35%) blamed themselves for late presentation, another one-fifth blamed the family, and similar numbers, blamed the patient (11%), the illness (8%) and the health care system (8%).

Amongst GPs who blamed themselves, (i) lack of confidence—'GPs are afraid to diagnose and initiate treatment'; (ii) lack of time—'screening symptoms are missed during short consultation'; (iii) therapeutic nihilism—'there is an absence of worthwhile treatment'; (iv) lack of (GP) education—'there is a lack of training in dementia diagnosis'; and (v) personal blame—'failure to diagnose by GPs', 'we don't look for it enough' were the main reasons given. A small minority ($n = 17$) saw no value whatsoever in early diagnosis: 'lack of urgency as early diagnosis has little effect on the progress', 'lack of benefit in knowing earlier', 'there is no proven advantage to early diagnosis'. Amongst those who blamed the patient or family, denial, stigma, embarrassment, misunderstanding (including the belief that cognitive decline was a normal part of ageing) and therapeutic nihilism were the main themes which emerged:

'Relatives do not bring the patient to the GPs attention'.

'High tolerance from patients and relatives of the vagaries of old age'.

'Patients are embarrassed to admit to memory problems'.

'Patients also present late because they feel there is no treatment'.

Accessibility of specialist services: GP needs and usage. Table 1 shows that fewer than half (43%) had immediate access to OAP services, and fewer again (41%) to GM services. Virtually no GP had immediate access to NP. The majority had access within 12 months to OAP (80%) and GM (96%), whilst only 12% had access to NP services. Data analysis revealed no significant difference between urban and rural GPs regarding time delays in accessing secondary services (OAP: $\chi^2 = 2.472$, $df = 1$, $p < 0.116$; GM: $\chi^2 = 0.108$, $df = 1$, $p < 0.743$; NP: $\chi^2 = 0.787$, $df = 1$, $p < 0.375$).

Focus group results

Socio-demographic profile of GPs. Five out of seven focus group GPs were male and all worked in a rural practice. Four were in practice for over ten years and two for five years or less. One GP gave no practice details.

Table 1. Time delays in accessing specialist geriatric and psycho-geriatric services for GPs

	Psychiatry of Old Age (OAP) (n = 293)	Geriatric Medicine (GM) (n = 292)	Neuro-Psychologist (NP) (n = 286)
Immediate Access	43%	41%	1%
Wait times > 3 months but < 1 year	37%	55%	11%
Wait time > 1 year	4%	3%	9%
No Access Publicly	15%	1%	76%
Don't Know	1%	0	3%

Obstacles to diagnosis. Focus group findings revealed the difficulties rural GPs had accessing locally based CT and MRI scans:

‘Even from a diagnostic end, if you want to get a CT scan done, you really don’t have access to CT scans . . . there is a kind of difference to what happens in Dublin’.

Despite this, a perception was held that rural doctors were more actively involved in dementia screening than their urban counterparts:

‘I think there’s basically a rural urban divide, for us it would be absolutely normal to take blood tests from our patients and refer them for x-rays, I mean that’s the difference a lot of Dublin GPs . . . would refer maybe to a hospital outpatient clinic’.

The long-term interpersonal nature of the patient-doctor relationship in rural communities also at times, militated against some GPs detecting dementia:

‘Very often you know these patients very very well and have seen them over many years . . . and maybe you don’t notice, because of *your* lack of memory . . . *their* lack of memory and then its really only when a crisis occurs, you know, something happens that sort of makes everybody stand back and say oh my God its really obvious’.and made it difficult for most to administer the MMSE:

‘The MMSE is quite distressing . . . to do with a patient you know, I think its quite an invasive test . . . I think part of the problem is that the minute you start doing it, its . . . very direct . . .’.

Stigma also prevented doctors from taking the initiative—‘It’s okay if *they* approach *you*’ and stigma and nihilism also prevented most from pursuing a diagnosis until such time as it became inevitable:

‘I think that the label is the problem. I think all of us (GPs) are reluctant to label somebody because that immediately puts them in a category of high dependency . . . so I think

all of us . . . you know we’ll muddle along in a grey area until . . . it’s clear a patient can’t manage on their own . . .’.

When asked, all GPs denied that financial incentives would facilitate the development of diagnostic systems however, several expressed a desire for better remuneration to assist in case management:

‘I think it wouldn’t be so much getting paid for doing the tests, . . . it may be much more successful to have some sort of a scheme whereby we were taught to really look after them [patients] and are paid to really look after them . . .’.

The education and training needs of UK and Irish based GPs have recently been reported (Cahill *et al.*, 2006; Downs *et al.*, 2006). Focus group findings revealed how rural GPs reported that current undergraduate and postgraduate curricula were insufficient. An interest was expressed in multi-pronged training programmes including problem-based and e-learning. On the topic of dementia guidelines, whilst an interest was expressed particularly for medico-legal and pharmacological guidelines, there was agreement that guidelines should not be overly prescriptive:

‘In particular guidelines about pharmacological interventions—when do you reduce, review or remove medications that are ineffective?’.

DISCUSSION

Despite public awareness campaigns and the excellent work of the Alzheimer’s Associations across the world, the belief that ageing results in cognitive decline, stigma, and denial by relatives and the individual to confront dementia (Eustace *et al.*, 2007) all remain important reasons why patients present late for diagnosis. Our findings also show that failure by GP’s to detect dementia due to lack of time or education, stigma or therapeutic nihilism are also critical barriers to its early detection. In fact, our

results reveal how GPs were four times more likely to blame themselves than the health care system and three times more likely to blame themselves than their patients for its late presentation. Whilst a definition of 'late' was not provided to GPs in the survey, it may be equally likely that self-blame and diagnostic uncertainty would be present amongst GPs even if patients with a suspected dementia presented early. This issue needs more consideration.

Our survey findings ($n = 300$) show that more than half (55%) the GPs waited a minimum of 3 months for GM consultation, more than a third for OAP services and for both services, immediate access was uncommon. Access to NP services were even more rare. Such time delays may further disadvantage patients and their families, since clinical treatments and access to some community services often require more specialist diagnostic input. Our focus group findings also showed how rural GPs felt geographically disadvantaged accessing diagnostic services including CT scans and MRI's. However, survey results showed no significant difference between the two groups regarding secondary service delays. This discrepancy may be caused by the fact that in rural areas unlike cities, CT scans and MRIs are not available locally and wait listing may be longer. Further work however needs to be undertaken to determine whether geographical disadvantage as highlighted in focus group findings is real or perceived.

Since 2001, those over 70 years in Ireland have free access to primary care services, including free anti-dementia drugs if prescribed. Most Irish GPs however are paid an annual capitation rate, irrespective of the demands older patients placed on their time; a policy which may disadvantage GPs financially since older patients with dementia, are more likely to have complex synergistic illnesses requiring multiple visits. As noted by Downs *et al.* (2006), the recent change in British GPs contracts whereby GPs managing some chronic illnesses are now better paid for improved care documentation and diagnostic compliance has application to dementia care in Ireland since our focus group findings suggest that access to and resource availability is a core necessity in dementia diagnosis in primary care. Immediate access to diagnostic resources might further overcome referral delays, as GPs could schedule scans and tests without first needing specialist input. Further research in this area is now warranted.

Several limitations to this research must be considered. Firstly, although the survey sample was randomly drawn, it is likely that participants were a biased group. Secondly, focus group participants

KEY POINTS

- GPs encounter diverse obstacles when diagnosing and managing patients with dementia
- Despite structural barriers, GPs are more likely to blame themselves for the late presentation of dementia in Ireland
- Stigma is a major obstacle preventing GPs from being more proactive in diagnosis
- GP training programmes supportive of management techniques now need to be developed

were a convenience sample and accordingly the data collected is not transferable. Thirdly, although questions were asked about GPs access to secondary services, the issue of the extent to which GPs relied on these services to diagnose or support their suspicions was not explored. Finally, whilst some rural/urban differences were explored in the survey and noted in the focus group, a more rigorous and comparative analysis of these differences was not the core focus of this study. This could be the subject of future research.

CONCLUSIONS

In conclusion, our findings provide compelling evidence that training and access to diagnostic services are only two of several different obstacles (both structural and ideological) that GPs encounter when attempting to diagnose dementia. Accordingly, whilst the larger sample ($n = 300$) could easily identify health policy and other social barriers which impeded their attempts to diagnose, ultimately they considered themselves primarily responsible for much of the late presentation of dementia in primary care. Whilst tackling GP's educational needs may be relatively easy and is likely to improve detection rates (Downs *et al.*, 2006), the problem of transferring knowledge to ultimately change ideology and practice (Fortinsky *et al.*, 1995), eradicate professional nihilism (Ilfie *et al.*, 2005) and improve management skills (including medication review, behavioural modifications, and referral to outside services) is more complex and requires more time. Future educational supports for GPs need to be developed which concentrate on these critical areas.

NOTES

1. The 1996 Census definition of urban/rural was used for classification.

2. The term late was not defined for GPs and therefore may have been open to different interpretations.

CONFLICT OF INTEREST

None.

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APPENDIX 1: INTERVIEW SCHEDULE —FOCUS GROUP

Questions from the Survey	Prompts for discussion around these topics
Have you had any specific training in dementia care? Would you welcome post-graduate training in dementia care?	Discussion around training included: the optimum way of approaching dementia specific training; the information needed or desired; different training modalities
How frequently do you diagnose dementia? Approximately how many cases of dementia have you diagnosed in the last year? What proportion of your patients are aged 65+?	Discussion around diagnostic frequency included: where diagnostic responsibility lies; whose responsibility it is to diagnose dementia and who would be best suited to diagnose dementia
What is the most difficult aspect of diagnosing dementia in your patients?	Discussion around diagnostic difficulties included: the impact of the diagnosis and the nature of this concern in relation to diagnosing; early diagnosis and disclosing. Information and services needed to improve diagnosis
Cognitive assessment tools and Diagnostic tests: Which cognitive assessment tool is in your view, the most reliable indicator of dementia? Which diagnostic tests do you regularly use to diagnose dementia?	Discussion around the tools and tests included: the role of reimbursement incentives; use and usefulness of guidelines and what content; feasibility of tools and tests; experiences of using tools and ordering tests; wait times and other factors
Do you tell your patients their diagnosis? What factors influence whether you tell a patient?	Discussion around the disclosure of a dementia diagnosis included: protocol in other European countries; professional dilemmas; capacity and comprehension; needs of all parties involved
Access to services: What is your access to each of the following services? Psychiatry of Older Age, Geriatrician, Neuropsychologist	Discussion around the access to services included: experiences accessing psychiatric; geriatric and neuropsychological services; the impact of improved access, link person etc.