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Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study

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Objective. The aim of this study was to explore the perspectives of primary care practitioners on the early diagnosis of dementia.

Methods. A total of 247 GPs, 146 community nurses, 36 practice nurses, 79 community mental health nurses and others working in a range of hospital, residential and community settings attended 24 one-day workshops in 21 cities and towns in the UK. A nominal group approach was used relating to the early diagnosis of dementia in the community.

Results. Groups agreed on the benefits and risks of early diagnosis of dementia; disagreed about screening for dementia, and about professional resistance to making the diagnosis; constructed comprehensive guidelines on diagnosis, but without much reference to resource implications; yet described actual local resource limitations in detail; and avoided dilemmas about dementia care by framing it as a specialist activity.

Conclusion. Practitioners situate dementia in a family context but do not yet use a disablement model of dementia which might reduce tensions about early diagnosis and the disclosure of the diagnosis. The term diagnosis could usefully be replaced by recognition, to aid this shift in model. Service gaps may emerge or widen if earlier diagnosis of dementia is pursued as a policy objective.

Keywords. Dementia, early diagnosis, primary care, screening.

Introduction

Between 1990 and 1998, the proportion of the European Union (EU) population aged over 65 increased from 14.5 to 15.9%, and now numbers ~60 million people.[1] A recent review of dementia prevalence studies in the EU estimated that 3.8 million people (6.4% of this age group) had dementia.[2] Given the ageing of the European population,[3–5] the incidence of dementia is likely to be 10 new cases per 1000 people per year, or 600 000 per year across the EU.

Evidence from the UK suggests that whatever the level of disability, the majority of people with dementia live in their own home.[6] The primary care team is therefore the first point of contact for people with dementia and their families, and is uniquely situated to play a central role both in establishing a diagnosis of dementia and in ongoing support and intervention.[7] In the UK, it has been estimated that a GP with a typical list size could expect a caseload of 10 and an incidence of 1.6 new patients with dementia per GP per year.[6.]

There is evidence that underdiagnosis is one of a number of deficiencies in both diagnosis and management of dementia in the primary care setting.[8–10] Survey data suggest that GPs feel inadequately trained to respond to the needs of people with dementia and their families.[11–13] These difficulties may reflect the problematic nature of dementia diagnosis and management (i.e. its uncertain aetiology and pathophysiology, high variability in symptoms and signs, and the absence of validated diagnostic tests or monitoring measures) rather than any general inadequacy within primary care teams.[14] The problem is an international one, with similar findings reported across Europe, North America and Australasia.[7]

As a result, it is estimated that half of dementia cases remain undiagnosed.[10,15] Early diagnosis allows the optimal use of recent therapeutic advances based on cholinesterase inhibitors, as well as allowing for individuals and families to be informed about, and introduced to appropriate agencies and support networks which can relieve the disabling psychological distress that carers

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may experience.[16] In addition, early diagnosis increases the opportunity for disclosing such a diagnosis to the person with dementia,[17] a course of action which is increasingly reported as positive by people with dementia.

Recent reviews of these issues have concluded that primary care practitioners need some kind of educational intervention in order to improve their response to dementia.[6,9] However, these educational agendas assume that the core problem in under-recognition of and under-response to dementia is lack of knowledge, despite the evidence that GPs can recognize dementia[18] and fail to change their management practice when screening instruments reveal new cases.[19] There may be other factors which influence professional activity around dementia recognition, and this paper explores this from the perspectives of primary care practitioners themselves.

Methods

The data discussed draw on a nationwide educational programme of multidisciplinary workshops held in the UK over a 3-month period. Each workshop was divided into four nominal groups containing an average of 20 participants. An adult learning approach was taken, using problem-solving methods and an emphasis of learning from experience as the main style of education.[20] Groups worked on a series of questions related to their practice and to the design of services. The educational foundations and evaluation of the workshops are described elsewhere.[21]

The nominal group approach was used to explore practice, nominal groups being potentially powerful learning and development tools.[22] They have a particular role in analysing health care problems[23] and can help bridge the gap between researchers and practitioners.[24] Discussions were facilitated by experienced GP tutors briefed to identify relevant experiences and knowledge and to encourage reflection on their use. A nominal group approach designed for ill-structured problems was chosen, to allow for disagreements over problem definition, and for potential solutions which overlapped or varied widely in specificity. This required the groups to generate ideas, confirm that they were addressing the same problem, analyse the content of the ideas, categorize ideas and clarify the items in each category.[25] The facilitators sought to achieve agreement on problems and opportunities, rather than seek prioritization and ranking, and to record the key points with as much explanatory detail as possible on posters, flip-charts or overheads. For resource reasons, audiotaping of discussions was not possible.

The records of the nominal groups' conclusions were collated and analysed as documents. Analysis was part quantitative (seeking frequent, infrequent and absent themes) and part interpretative (seeking evidence of interests, perspectives and presuppositions).[26,27] Three researchers from different professional backgrounds (academic general practice, academic social care and postgraduate professional education) undertook thematic analysis, initially separately, and agreement was achieved through discussion. This analysis draws on the range of discussions about the process of diagnosis.

Results

The workshops, three in London and one in each of 21 other towns and cities, attracted 990 participants, including 247 GPs, 146 community nurses, 36 practice nurses, 79 community mental health nurses and others working in a range of hospital, residential and community settings.

Seven main themes emerged from the analysis of the workshops. They were:

(i) agreement about the advantages of early diagnosis of dementia;
(ii) agreement about the hazards of early diagnosis;
(iii) differences in opinion about screening for dementia, and in the value of screening and diagnostic tools;
(iv) competence in constructing pathways for differential diagnosis, investigation and management of dementia coupled with only general awareness of the resource implications of such efforts;
(v) differences of opinion about professional resistance to early diagnosis;
(vi) avoidance of dilemmas; and
(vi) rich description of problems in service provision coupled with limited analysis of ways of overcoming these problems.

We will describe these themes in detail. Text in bold represents common themes, and text in italics represents a report from one or two workshops.

Advantages of early diagnosis

All workshops were able to identify the advantages of early recognition of dementia for patients, relatives and services, although the main beneficiaries were families. Advantages to patients included **reducing uncertainty** about and **coming to terms** with the diagnosis, **excluding remediable causes** (however rare), **planning support** and **avoiding crises**. Families would benefit from stabilized family dynamics because "*more than one person is affected by dementia*", awareness of **prognosis** and the **disease course**, time to **organize support and plan for the future**, opportunities to make appropriate **legal arrangements**, time to consider **genetic counselling**, a better quality of life through enhanced knowledge and anticipation of problems. Three workshops described advantages to local services in aiming for earlier diagnosis of dementia, including data collection for **workload and resource planning**, greater leverage for **resources for relevant community services** and, for practitioners, and the slow build up of GP skills and expertise.

Hazards of early diagnosis

The workshops were all able to list many reasons why early recognition of dementia might pose a hazard to patients, families, professionals and local services. For patients, disclosing the diagnosis could be destructive, creating **anxiety** and provoking a **depressive reaction** to the "*bleak outlook*". **Labelling** and **stigma** were invoked as factors which might alter the relationships between the patient and others, in one workshop leading to the concern that doctors would overlook other pathologies. Screening and assessment methods were themselves thought able to increase fear in patients and their family members. Relatives could also experience **shame**, **stigma**, **anxiety and isolation**; they might also receive a diagnosis when they need a prognosis, and their apprehension at the perceived tasks ahead of them might alter their relationship with the patient. One workshop asked "*does everyone want to have early recognition*?" and "*who does it benefit*?" All of these problems could be magnified if support and resources were not forthcoming. Professionals risked making **diagnostic errors** and labelling the patient prematurely, with potential damage to the patient, the family and relationships with the GP. Hazards to local **service budgets** were obvious to all workshops, particularly when the **rule of halves** was invoked to predict a doubling in the number of cases if diagnostic efforts increased. Another common theme was the **pressure** that relatives would put on GPs to refer to (already stretched) specialist services, or to prescribe expensive anti-dementia medication of uncertain value.

Screening

There was evident confusion in the workshops over the term screening, with some debating the value of '*formal*' (whole or subpopulation) screening using the 75 and over checks as the vehicle, and other rejecting this approach in favour of **opportunistic screening**. Whole or targeted population screening was proposed by some on the grounds that dementia was common enough to warrant it, and that most cases had yet to be identified, but there were anxieties about which groups to target. Opportunistic screening was defended on grounds of limited resources, both in general practice and in specialist services. No workshop used the terms 'case finding' or 'assessment' as alternatives to 'screening', when discussing individual rather than population perspectives. There was no agreement between workshops about whether the new anti-dementia medication meant that early treatment had become more effective than late treatment, nor was there agreement on a suitable test. Existing assessment tools, such as the MMSE and the AMTS, were seen as too long for routine use in general practice, and anyway not diagnostic, whilst practitioners faced real problems in reaching a diagnosis and needed assistance. Two workshops made explicit comments about the **ethics of screening**, the problems of obtaining informed consent, the threat of screening to the psychological stability of patients and the problem of overcoming taboos about dementia to allow screening to be accepted.

Diagnosis and care pathways

The workshops had no difficulties in listing the **investigations** that were appropriate on first suspicion of dementia, the importance of an **informant history**, the **differential diagnosis** of the dementias and its relevance to clinical practice, and the contributions of different **specialists in health and social care**. All were able to describe ideal care pathways (usually beginning with the 75 and over checks), but most documented **uncertainties about referral criteria** and were concerned that local services were **underequipped** to support patients and their families. Two specific resource issues were identified: social care was described as '*unable to deliver*', lacking **continuity** in care provision and limited access to respite care; primary care was described as unable to develop **systematic management processes**, particularly if the benefits of assessment in the home were emphasized. Although all workshops expressed reservations about the **resource implications** of implementing a programme of early diagnosis of dementia, only two documented these implications quantitatively. One estimated that each GP would have 15 patients with dementia, but through efforts at early screening would also generate 5–10 'false positives'. The other invoked the rule of halves to predict a doubling of caseload if early recognition of dementia was completely effective. Several workshops documented estimates of prevalence, without using them to predict the consequences of introducing an early diagnosis programme. These estimates ranged from a 3-fold underestimate to a 5-fold overestimate, most being overestimates.

Professional resistance to diagnosis

Three different perspectives on possible professional resistance to early diagnosis emerged from the workshop reports. One accepted that **resistance to diagnosis** occurred, for a number of reasons. A second argued that **resistance to disclosure** occurred, but not to diagnosis, again for a number of reasons. The third denied any professional resistance, seeing dementia as a **physical disease** for which there was now a treatment. Workshops favouring the first perspective described the difficulty for GPs in making the diagnosis of dementia, in particular distinguishing dementia from **normal ageing**, and the implications of the diagnosis for the patient and family. These workshops tended to stress that practitioners felt **inadequately trained** for the task of early diagnosis, and that the diagnosis was **difficult to accept** for professionals as well as patients—"*we know the implications of the disease process*". Lack of time, and of confidence, were also noted as contributory factors by this group of workshops, and euphemisms for dementia were discussed—"*should we call it memory loss in the early stages*?" The workshops that focused on resistance to disclosure emphasized the negative effects of the diagnosis on patients and families and adopted a protective approach, whilst the third group (a minority of three workshops) did the opposite, making dementia into a disease within the medical model—"*the majority (of professionals) do not and have no reason to resist*". "*Insight into the diagnosis is almost a relief but until recently nothing could be done. Now (dementia) is worthwhile to diagnose*." And "*Relatives feel that there may be a treatment and a cure in the future*".

Avoidance of dilemmas

A number of discussions led to descriptions of avoidant behaviour. For example, when asked how they would approach telling someone that a relative with Alzheimer's disease was unsuitable for treatment with acetyl cholinesterase inhibitors, one workshop concluded that it "*would not tell anyone they are unsuitable for treatment, but would refer them to social services and the Alzheimer's Society.*" Several workshops argued that the diagnostic task (and therefore the task of disclosure) belonged to specialists, not GPs, who were described as **insufficiently experienced**.

Descriptive, not analytic?

The workshops produced rich descriptions of the advantages and disadvantages of early diagnosis, the difficulties of distinguishing between early dementia and other changes in older individuals, the inexperience and lack of skill of primary care professionals, and the limited resources or unresponsiveness of local services. Only a few workshops were able to move from those descriptions to propose changes in practice and organization, and argue that improving dementia care in the community could impact on other sorts of provision. "*The advantages of promoting early recognition of dementia in the community including shifting budgets—we will need more physiotherapists, district nurses, community psychiatric nurses, occupational therapists and nursing home places to respond to an ageing population.*"

Discussion

The data reported here reflect participants' presentation of their own experiences and not the perspectives of those receiving diagnosis or assessment. The workshops attracted those with interest in dementia and in older patients, who may not represent the broader population of practitioners. It may also be possible that the multiprofessional format restricted in-depth discussion of particular professional concerns or presented an overly optimistic view of inter-agency co-operation. The nominal group approach, and the collation of conclusions from groups may have missed important and useful detail in practitioners' accounts of their experiences.

Nevertheless, the data obtained from a large number of practitioners appear to add important details to our understanding of dementia in primary care. We wish to emphasize three issues arising from this analysis. Across Europe, negative perceptions of dementia as a stigmatizing disease are widespread,[28] and thus may influence logical calls for increased recognition. In this study, primary care practitioners appear to apply the principle of 'doing no harm' to early diagnosis of a condition widely accepted as negative and life-changing. They seemed conscious of the risks of early recognition and were able to present examples of these at patient, family, service or agency levels. There was little evidence of a social model of disability around dementia informing their perspective that patients had rights to a diagnosis, information and choices about routes or methods of assessment. While early diagnosis is emerging as a policy objective at the level of individual consultations, professionals in practice see it as a complex arena in which a 'best interests' approach continues to guide assessment and management. New English organizational structures such as Primary Care Trusts or implementation teams working around the *National Service Framework for Older People*[29] represent opportune initiatives in which to consider the translation of policy into service delivery.

Secondly, the data suggest a need to consider the terms diagnosis and recognition. What is meant by diagnosis may be more usefully expressed by the term recognition and all this implies about a continuing and evolving relationship between the patient and practitioner. Diagnosis is one element of recognition but, as the workshops illustrated, this process can be lengthy, involve multiple assessments and communications and, of course, can be one of a set of diagnoses around other co-morbidities. Recognition may also relate to the movement of family member(s) into the orbit of informal care and its emotional and instrumental labour. This is one outcome of an early diagnosis, and the workshops were clear that family members were key supports both to those with dementia and also to services. This process involves further acknowledgement by the primary care team of the possible separate needs of carers and the changing nature of support required.

Thirdly, the workshops were aware of resource implications of early diagnosis and evidently pessimistic about the capacity of local services to respond to the implications for effective support. As noted above, most were able to cite examples of service deficiencies, though some of this related to services for people with high levels of need. A service or support 'gap' may well be emerging for those with the diagnosis of dementia (receiving medication or otherwise) who are as yet ineligible for services. Practitioners, people with early dementia and their families may wish to develop a 'vision' of what is supportive at local level and feed this into the commissioning processes: the alternative seems an inevitable focus on 'beds', 'places' and other institutional models of care. British experience may be helpful for others, for, as Lawlor *et al.* report, in some ways Britain is relatively sophisticated in diagnosing and differentiating between the dementias.[30] Others may watch with interest to see if these developments enable effective responses to early recognition at primary and social care levels.

Several positive elements were also revealed by the workshops which may give cause for optimism. Primary care practitioners put the process of diagnosis into the context of patients' lives and their relationships. The advantages and hazards of early diagnosis were seen from the perspectives of the patient, family, practitioner and team. The workshop format may have produced some 'ideal' answers, of course, and such a method may not permit too deep a discussion of the personal difficulties of managing distress and uncertainty, particularly when treatment is not considered beneficial. This management of the 'uncertainty principle' may be as important to include in professional education as the imparting or development of knowledge.[31] Some of the generalized concerns about the capacity of services to respond to people with early dementia may reflect the practitioners' own difficulties in meeting families' needs for support over long periods. Dementia is one example of a condition that seems potentially to touch the 'raw edges' where professional and personal boundaries meet.[32]

Finally, raising awareness of dementia as a policy objective may need to focus less on prevalence and apocalyptic demography and more on moving support centre stage to accompany medication, when appropriate, but acknowledging that the need for support and services will remain and grow. Warner and Furnish have recommended setting targets across Europe to increase the quality of assessment and diagnosis of early dementia,[33] but the workshops revealed that practitioners who grapple with issues around early diagnosis in dementia may be providing important reflections on the broader service landscape: such experience could be tapped to inform service development and professional education. 'Practice-based evidence'[34] will be an important element of the capacity of primary care practitioners to respond to the challenge of early recognition and diagnosis of dementia.

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