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Dementia management in France

Health care and support services in the community

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Abstract In France, a wide range of care and support services exist for community dwelling people with Alzheimer's disease (AD). These are coordinated by the general practitioner (GP). We investigated interventions that were 'prescribed' by French GPs and analysed their perceived barriers to arranging these. Thirty-nine percent of GPs responded to a postal survey, which was sent to 1105 physicians belonging to the Sentinel GP Research Network and to 524 GPs consulting in the Rhône-Alpes region of France. Fifty percent of patients were treated with acetyl-cholinesterase inhibitors and the following other support services were used: home help (63%), nursing care (48%) and physiotherapy (35%). Although GPs acknowledged carers' need for emotional support, only minimal levels of other interventions such as day care (12%) and psychotherapeutic interventions (12%) were prescribed. Reasons for under-use included non-availability and carers' reluctance to undergo psychotherapy. Lack of integrated community care services, insufficient information on services, lack of collaboration between health professionals and the frequent absence of a reliable carer were considered the most important barriers to the effective support of people with dementia in primary health care settings.

Keywords Alzheimer's disease; caregiver intervention; community services; general practitioner; public health care

In France, the management of Alzheimer's disease (AD) and related disorders has become an important public health issue. This is not only explained by the high number of people with dementia (850,000 cases)

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and the number of families touched by the disease (it is estimated that 3,000,000 people have a close relative with AD) (Office Parlementaire d'Evaluation des Politiques de Santé, 2005), but also by the negative impact of the disease on family caregivers. Although there are a variety of community services that focus on medical, instrumental and technical aspects of care, interventions targeting emotional support remain rare. This situation is not confined to AD but for disability and chronic illness in general, irrespective of the initial presenting condition. In France, as in many European countries, the management of AD is incorporated within general policies for disability, and community resources are divided into health care and social services, with few mechanisms in place for adequate coordination across services.

The most frequent community health care services administered to individuals with dementia at home are nursing care, physiotherapy and speech therapy. Rehabilitation and cognitive stimulation programmes are mainly offered by *Consultations Mémoire de Proximité* (memory centres) and by *Centres Mémoires de Ressources et de Recherche* (CMRR), which are research resource memory centres that play a leading role in early diagnosis and management of dementia. Common support and care facilities offered by social services are home help and geriatric care assistance, which are mainly delivered by organizations such as associations or companies. These are financed on a communal or a departmental level, as France is divided into 'departments' that have the main responsibility for administering and financing social support.

Psychosocial care has an ambiguous status: translated into French the term 'psychosocial' is described as 'medico-social', reflecting a potentially medical focus to dementia care and management. It is most frequently offered by health services and by public or private associations in the form of respite care. Interventions offering emotional support, psychotherapy and psycho-educational programmes for caregivers do not appear to be widely used. Provision of emotional support may well lie with family physicians (GPs) who by default act as the main confidantes to both patient and caregiver, throughout the course of the illness. In most cases the GP will have known the family for a long time and GPs are often the only medical practitioners who see people at home, allowing them to acquire an impression of the living conditions and the social environment of the person with dementia. The GP is therefore in a good position to evaluate potential barriers to effective care and also occupies a central position in arranging care and support. The results of an initial survey on diagnostic practices of French Sentinel,[1] doctors confirmed that GPs in France, like their counterparts in the Netherlands (Van Hout, Vernooij-Dassen, Bakker, Blom, & Grol, 2000), felt that they have little to offer in diagnosing dementia. This perception appeared to result in poor motivation to initiate the diagnostic work-up that is necessary for a suspected dementia, the under-diagnosis of AD, poor identification of the condition in the early stages and embarrassment about disclosure of diagnosis (Cantegreil-Kallen et al., 2003). A study from the UK suggests that GPs believe that psychosocial follow-up support for patients and caregivers is a very difficult task in dementia management (Turner et al., 2004).

The present study investigated the interventions 'prescribed' by French GPs for people with dementia and family caregivers. By developing a baseline of what support is actually arranged by GPs and gaining a better understanding of the dilemmas that they face, including their perceived barriers to dementia management, future intervention may then focus on assisting them to overcome the obstacles they encounter in arranging psychosocial support for people with dementia and their family caregivers.

Methods

Data were collected via a postal questionnaire sent out to 1629 GPs of which 1105 were research GPs belonging to the French national Sentinel network of INSERM. In addition, to broaden our sample from research-orientated GPs, to those that were clinical practice-based only, all 5897 GPs from the Rhône-Alpes were also approached. Of these, 524 volunteered and were included in data collection, in other words, they were sent the postal questionnaire. Statistical analysis did not show any significant differences in response rates or content between Sentinel 'research' doctors and Rhône-Alpes 'clinical practitioner' GPs, so we analysed the data as a whole.

The questionnaire was designed by a special working group consisting of four members of the Sentinel network and six GPs from the Rhône-Alpes region. It consisted of yes/no and open-ended questions on clinical practice and perceived barriers to dementia management. GPs were asked to fill out the form during the consultation of the very next patient they would see diagnosed with AD, following receipt of the questionnaire. Thus, information reported by the GP in the questionnaire related to one patient only. Prescribed community care and support were divided into: rehabilitation therapy; home-help support services; nursing care; psychological interventions; respite care. For each intervention, the GPs were asked if they had prescribed it (yes/no option). If 'yes', they were asked whether they considered the particular intervention effective (yes/no option); if 'no', they had to explain why. GPs' perception of their knowledge of existing community sources and of collaboration with other health professionals were evaluated by yes/no responses. Obstacles were analysed by open-ended questions.

Results

Participant GPs and their patients

Six hundred and thirty-five questionnaires were returned (a response rate of 39%) of which four were spoiled and 631 were eligible for analysis. Of these, only 619 described a patient and 12 did not complete the questions on practice, but responded to other items such as the perceived barriers. The mean age of the responding GPs (N = 631) was 50 (range 31–78) years and 76 percent were male. Fifty-eight percent worked in an urban area, and 39 percent in a rural area, with 3 percent failing to specify their practice location. On average, participating GPs reported having four patients diagnosed with AD (of which one was included in the questionnaire study).

Not surprisingly, all patients reported on had been diagnosed with AD. The mean age of patients (N = 619) was 80 years, 67 percent were female and on average GPs reported that they had been diagnosed for 32 months, followed by ongoing support by the GP. Sixty-eight percent had a family caregiver who was usually a spouse (74%), and 32 percent were living alone. Half of the individuals with dementia described by their GP were being treated with a cholinesterase inhibitor.

GP perceptions of the utility of psychosocial intervention and their usage

The following rehabilitative interventions were 'prescribed' by GPs for the patient described in the questionnaire: speech therapy (12%), cognitive stimulation therapy (29%) and physiotherapy sessions (35%). Home help interventions had been prescribed in 63 percent of cases and geriatric care assistance was arranged for 16 percent of patients. Nursing care had been offered to 48 percent of patients. Psychological support had been prescribed for 12 percent of patients and 15 percent of the total of 412 family caregivers. Respite care was offered in the form of day care by 12 percent of the participating GPs and 10 percent arranged temporary residential care for the patient.

GPs reported that some interventions were not always available and were therefore not often used. These were: cognitive stimulation therapy (in 44% of cases), educational programmes for caregivers (40%), day-care (31%), temporary residential (respite) care (26%), psychological support for the caregiver (20%) or for the patient (15%) and geriatric care assistance (11%). Speech therapy, nursing care, physiotherapy and home help were unavailable in less than 5 percent of cases. Non-compliance with treatment (for patient or caregiver) was reported as follows: psychological support for the patient (54%); speech therapy (41%); cognitive stimulation (41%);

psychological support for the caregiver (40%); day care (32%); physiotherapy (31%); temporary residential care (30%); educational programmes for carers (25%); geriatric care assistance (21%); home help (21%); nursing care (19%).

GPs were asked about their views on the perceived effectiveness or importance of prescribed support in general (i.e. not necessarily related to the particular individual). Their responses on what was important were as follows: nursing care (89%); home help (86%); geriatric care assistance (83%); respite care (75%); emotional support for the caregiver (69%); emotional support to the patient (62%); physiotherapy (71%); speech therapy and cognitive stimulation (63%).

GP perception of the barriers to use of psychosocial support

GPs' views of their knowledge of dementia management in community dwelling patients were investigated: 56 percent of respondents thought they were insufficiently informed of existing community care services for families. Collaboration with social workers was estimated to be difficult by 58 percent of the participating doctors. Fewer (34%) saw collaboration with other health professionals as difficult.

A final open-ended question addressed the issue of perceived obstacles to adequate dementia management in general practice. Two hundred and fifty GPs responded to this particular question, which was a general item that did not refer to the particular patient described in the questionnaire: 66 percent of the GPs cited the lack of a reliable informant, 21 percent mentioned patients' and caregivers' reluctance and non-adherence to psychosocial interventions. Other perceived barriers were: financial problems encountered by families (16%); lack of education about dementia among other health professionals making collaboration with the GP difficult (5%); GPs' own lack of knowledge of AD (5%).

Discussion

The low response rate (39%) makes it difficult to generalize the results, but this is not uncommon in postal surveys. Nevertheless, the information collected provides an initial map that can contribute to a better understanding of the way some French GPs prescribe interventions and use community resources.

Half of the patients included in the survey were treated with anti-dementia drugs, a finding that is consistent with a recent survey by Waldemar and colleagues (2005). They compared use of anticholinesterase inhibitors across Europe and noted that the highest proportion treated was in France, where 51 percent received one of these drugs. French physicians prescribe almost three times more anticholinesterase drugs as compared to the UK and six times more as compared to the Netherlands. There are two potential reasons for this. The first relates to culture, as traditionally French GPs are generally in favour of prescribing pharmacotherapy for most health-related conditions. The second relates to referral practices, since in France, nine out of ten dementia-suspected patients are referred to a specialist (Dartigues et al., 2005). Thus, patients with a confirmed diagnosis of AD made by a neurologist or geriatric specialist are automatically treated with a cholinesterase inhibitor. Of the non-pharmacological interventions used, provision of home help was the most frequent (two patients out of three). This may be because patients described by the GP in the questionnaire were in moderate to later stages of the condition, or that caregivers were overburdened. Nursing care was prescribed to half of the patients, again suggesting that GPs were describing patients with advanced disability, co-morbid pathology or the need for nurse involvement in the administration of medication to patients, even though two-thirds were living with a caregiver.

The most frequently prescribed therapeutic intervention was physiotherapy (one patient out of three). Two possible explanations are: (1) a number of patients had a vascular or mixed dementia, or had other co morbid conditions such as frequent falls; (2) several participating GPs reported that they felt they had little to offer AD patients living without a carer and that their concern led them to arrange physiotherapy, since in France the physiotherapist is one of the few health care professionals who visit patients at home. Thus GPs appeared to use physiotherapy as a way of monitoring socially isolated people with dementia.

Respite care was not commonly used, with only one out of eight patients given day care, usually due to reported poor availability of this. Moreover, the geographical distribution of day and residential care units are not homogeneous and access to day care not adequately flexible (Office Parlementaire d'Evaluation des Politiques de Santé, 2005). Psychological support was particularly poorly prescribed. Although several factors may contribute towards the low prescription rate, such as non-reimbursement by Social Security for the costs of psychologists consulting in the community and the fact that training programmes are only offered in memory clinics, the predominant cause was poor adherence by patient and caregiver. GPs reported that caregivers are quite reluctant to accept emotional support, in particular when it concerns interventions by a psychologist. One explanation for this was that caregivers seemed ashamed at not being able to carry on without professional help. As a consequence, GPs believe that they play a central but time-consuming role in providing emotional support. Additionally, more than half of the physicians felt insufficiently informed about community support and care services. This may explain why GPs see pharmacotherapy as an important first line of action in the care of people with dementia.

Implications for practice

A noteworthy point yielded by the survey is the gap or poor coordination between health and social care workers. This may be due to the historical separation of health and social sectors with respect to purpose, education, responsibilities and funding. The results of another survey on collaboration between the medical and social sectors in the Rhône-Alpes region showed that 62 percent of GPs do not wish to be involved in management of social aspects of dementia (Gayrard & Harzo, 2005). This is even more regrettable as the French primary care systems do not appear to foresee the benefits of case management. Recently, two service innovations have been introduced in order to facilitate access to community care services and to integrate health and social care: *Réseaux Gérontologiques*, gerontological networks, and *Centres Locaux d'Information et de Coordination* (CLIC). The goals of a gerontological network are to enhance access to diagnosis and to provide coordinated multidisciplinary care to older people living in the community. The GP plays a pivotal role in this multidisciplinary care approach. CLICs are local centres for information and coordination.

In September 2004, the government presented the 'Plan Alzheimer et maladies apparentées 2004–2007' (the action plan for AD and related disorders 2004–2007) (Ministère des solidarités, de la santé et de la famille, 2005). The plan develops ten goals, focused on well-being and quality of life of people with AD or related disorders and their families. The priorities outlined are:

1. recognition of AD and related disorders as a long-term illness with entitlements to 100 percent reimbursement of health-care costs by Social Security;
2. supportive measures for patients and caregivers by the promotion of a wide range of community services (e.g. night-time home care), substantial increase in respite and residential care;
3. promotion of early diagnosis: a considerable budget will be dedicated to enforcement and creation of new *Centres Mémoire de Ressources et de Recherche*;
4. support and education of formal and informal care givers;
5. development and expansion of small assisted living units and a substantial increase in the number of places in day care facilities; simultaneously, gerontological multidisciplinary networks will be developed;

6. adaptation of residential care to promote good design and provide medical care;
7. education of professional staff and volunteers;
8. development of short-term care hospital departments in order to avoid the traditional emergency ward pattern of admission to hospital, associated with follow-up care at home after discharge from hospital;
9. establishing recommendations of clinical practice with respect to young patients;
10. increase of research on developing clinical practice.

Thus, current policy in France aims to provide conditions that allow older people to live at home for as long as possible, but to achieve this aspiration joint collaboration and coordination between different health care and social services will be required, underpinned by access to a multidisciplinary team approach.

Conclusions

The broad patterns outlined in this study reflect commonly encountered difficulties in primary care dementia management reported in the literature (Iliffe et al., 2005). Elements of existing services are fragmented and rarely coordinated. Moreover, the pattern of services on offer do not seem to match the desires of people with dementia and caregivers, who do not always benefit from existing support, because they do not take it up. Future research is needed to explore why this is. The consequence for dementia management in France is therefore orientated towards medical health care and pharmacotherapy, despite a general consensus that emotional support is important. Reluctance to uptake particular interventions requires further research, since the efficacy of psychotherapeutic intervention cannot be examined, if treatment compliance or therapeutic engagement remains problematic.

At national level, current trends focus on support and respite for caregivers. However these may be different at particular points in time and may depend on factors related to family demand and the stage of the disease process. Providing variety of support including relief to caregivers at all stages, rather than only during late stages, as is currently the case, is important if caregiver exhaustion is to be prevented. Therefore, integrated needs-led care management is essential. Policy benchmarking for active case management may be needed to improve coordination between health care and social support services. Recent innovations such as community-based multidisciplinary geriatric teams (*Réseaux gérontologiques*) and geriatric care support services (CLICs), provide a promising framework whereby, if developed nationwide, the aspirations of current policy in France may be realized. However, evaluation of *Réseaux gérontologiques* and CLIC-type service innovations will be needed prior to large-scale implementation.

Note

1. The Sentinel network consists of some 1200 volunteer GPs across France, who participate in scientific research, conducted by INSERM (Institut National de la Santé et de la Recherche Médicale), a public organization that undertakes bio-medical research and evaluation of health practices, in the full range of diseases that exist in the general population.

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