Community care for patients with idiopathic parkinsons disease

NEUROLOGISTS are comparatively rare in the United Kingdom, there being approximately one whole time equivalent neurologist per 300 000 of the population,[1] and it is sometimes assumed that neurological problems too are rare. However, in primary care they are extremely common. Neurovascular disease is the second largest cause of death,[2] and it is the most frequent serious neurological problem for which patients consult general practitioners.[3] Epilepsy, parkinsons disease, multiple sclerosis and dementia also incur long-term difficulties about which patients and their families consult general practitioners. Many doctors, particularly if they undertook their hospital training in district hospitals, received little specialist teaching on how to treat and advise on these serious conditions. Without locally accessible specialist support, doctors are wary about learning with or on the patients who consult them. Parkinsons disease affects about three or four patients on the average general practitioner's list;[4] it is an example of a condition which is common, but not quite common enough for general practitioners to gain expertise and confidence in managing it. Bearing in mind these learning deficits, the literature review on idiopathic parkinsons disease appearing in this issue of the *Journal* is to be welcomed.[5]

The Parkinsons Disease Society has recently produced a helpful guide for purchasers on patients' needs, and the services that might be provided in a model district.[6] The society describes stages of the illness which are associated with different health needs. At first, patients may have tremor and/or stiffness. They need a specialist opinion to establish the diagnosis, as essential tremor and neurovascular disease can be confused with parkinsons disease. Patients may be shocked by the diagnosis, or occasionally, if there has been uncertainty or delay, they may be relieved. At this stage they will need counselling and information about the condition and its social implications, for example the necessity of informing car insurers and the Driver and Vehicle Licensing Centre (DVLC).

Drugs provide effective control of symptoms for, on average, two to five years. After this they are less effective and patients have increasing problems with mobility. Parkinsons disease is the commonest risk factor for falls in those aged over 60 years.[7] Driving, employment, finances and housing may consequently be at risk. After about 10 years, the drugs may become ineffective and/or cause difficult side effects. A terminal picture of dysarthria, dysphagia, dementia, incontinence and pressure sores often creates burnout even in the most caring relatives. General practitioners too may feel helpless, as they are generally the most familiar and accessible of senior medical staff to families, but they are relatively impotent when it comes to providing appropriate services for patients with parkinsons disease such as respite or community care. The document produced by the Parkinsons Disease Society spells out the personnel and skills that districts should provide to help patients and their families cope during each stage of the illness.

How do patients and their families cope? Pinder[8] interviewed 15 patients in depth and described their responses which were in some ways similar to those described by Kubler-Ross[9] and Parkes[10] in the context of terminal care. Pinder described some patients who, when faced with ignorance and uncertainty, took up a seeking strategy whereby they sought as much information as they could find. At the other extreme, she found avoiders who would rather not know or who selected information to suit themselves. In the middle, she described weavers who alternated between seeking and denying as their way of surviving emotionally.

A large study of psychological responses to the experience of the progression of parkinsons disease described each stepwise loss of function as a challenge to the coping mechanisms of patients and their families, and as a potential trigger for depression.[11] The biological process and patients' cognitions and feelings are intertwined, and their need for information and support changes as the disease evolves. The fact that emotional and informational needs vary, and that the families of sufferers frequently have different needs from the sufferer, is difficult for the family doctor.

Pinder interviewed 18 general practitioners in depth to see how they coped.[8] The disease posed demands for technical and affective competence. Some doctors felt that they lacked these and that they needed to protect themselves from a sense of ignorance, uncertainty or failure. They described ways in which they avoided confronting the problems presented, such as by scheduling their time tightly. In this way, they were able to limit the time spent and involvement with such patients, and thus were able to defend themselves. Other doctors scheduled their time flexibly, just to listen. They recognized this had emotional costs for them and looked for advice and support from their colleagues. Perhaps doctors can be weavers too, sometimes giving the time to listen and to advise and, at other times, not. But the idea that some doctors take on more patients as a defence against involvement is interesting, and perhaps tallies with the work of Howie and colleagues.[12]

How can management be improved in the future? The Parkinsons Disease Society document describes the skills, resources and time which would be ideal.[6] The society acknowledges that its estimates are not based on a large amount of published evidence. There is a need for a systematic review of what has been done to evaluate services for patients with parkinsons disease, and for rigorous health services research, with the development of appropriate outcome measures. A promising sign is the funding of a large trial to assess the effectiveness of specialist nurses in parkinsons disease working in the community (Jarman B, personal communication, 1994).

In the context of commissioning and providing services, there is a place for presenting and discussing visions of what might be created, as the Parkinsons Disease Society have done.[6] The society's proposal that each district of approximately 500 parkinsons disease patients should have a full-time medical specialist with a multidisciplinary team of two physiotherapists, two occupational therapists and up to two speech therapists initially seemed excessive. However, the society's vision was worth exploring further.

The society acknowledged that the specialist could be a geriatrician or neurologist, but it is the latter who are in short supply. There are, on average, three geriatricians and one neurologist in the National Health Service for each locality with a population of a quarter of a million people.[13] As the incidence and chronicity (prevalence) of neurological problems is high, specialists who provide continuing care for patients with neurological problems may reasonably fear overwork and burnout. Purchasers who recognize this dilemma might encourage them to develop functional teams. Individual neurologists and geriatricians could continue to diagnose routine neurological problems referred to them. In addition, they could subspecialize so that each might have a specific input in a multidisciplinary team which focused, for example, on the diagnosis and continuing care of the big three: stroke, the epilepsies, and the degenerative disorders, which include alzheimers disease, parkinsons disease and motor neurone disease. With district teams like this, specialists would not need to fear professional isolation, and patients with neurological disorders would be more likely to receive the seamless service they need.

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General practitioners' low morale: reasons and solutions

> 'I just feel I am not valued any longer.'
>
> 'I feel that patients no longer value the service I give them.'
>
> 'It appears that the family health services authority no longer has the same relationship [with general practitioners], and the government doesn't value the services we give.'
>
> 'I just feel devalued.'

RECEIVING comments like these from keen general practitioners attending its seminars, the Royal College of General Practitioners has decided to take action.

There is good evidence of declining recruitment in vocational training. The number in vocational training posts fell by 17% in 1991, and in 1990 there was a decrease for the first time in the number of certificates issued by the Joint Committee on Postgraduate Training for General Practice (*Doctors in general practice 1979–91*, NHS statistical bulletin). It therefore appears that general practice is losing its ability to attract its share of the best graduates from medical schools, notwithstanding increased investment in staff and curricular time for general practice. General practitioners are also retiring at an earlier age and the Medical Practices Committee noted that the number of doctors over the age of 60 years had halved in the 10 years between 1982 and 1992 (Medical Practices Committee, *Chairman's report,* 1993). At the same time there is strong anecdotal evidence of low morale among established general practitioners, and although this is not universal it is prevalent enough to cause the RCGP, as the academic body of the discipline, considerable concern.

At present all countries are facing similar problems of meeting the demands of providing comprehensive health care and social care.[1] Increased expectations of populations who are living longer and surviving because of expensive medical technology, with its general inflationary costs, are bringing about many changes in the delivery of health care. Some general practitioners, however, see the changes as a chance to flourish, and not since the post-charter days of the late 1960s has general practice had such an opportunity to become the major clinical force in British medicine.[2]

In 1992 the council of the RCGP undertook a survey of a 15% random sample of principals aged from 25 to 30 years (joint RCGP/Medical Women's Federation initiative). This survey used a Delphi technique to identify the most common problems (for example, with career structure, career fulfilment and education) and trends, that would form the basis for discussion groups. The negative feeling identified was centred on lack of career trajectories (for example, views that unlike one's equally intelligent and qualified contemporaries in other walks of life, once a principal there is nothing else to aim for). Negative feeling was also based on predictable factors such as antisocial hours, difficulties in defending family time, unfair distribution of workload within the practice partnership, and opportunistic costs to good patient care of the bureaucratic load imposed by the 1990 contract for general practitioners.

In order to find out whether these concerns were confined to relatively junior principals, or were more pervasive, the survey was repeated with principals aged from 30 to 45 years, and found the same problems, together with increasing discontent with financial and workload arrangements within practice partnerships. Behind these immediate concerns loomed uncertainty about the future of general practice and about the evolution of the National Health Service reforms and their long-term outcomes.[3]

Out-of-hours calls have increased and accelerated since 1990, which might reflect general practitioners' willingness to visit or