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The Role of a Movement Disorders Clinic

Abstract:

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Abstract

Ireland's ageing population will result in a substantial increase in neurodegenerative disease with a projected increase in prevalence of Idiopathic Parkinson's disease (IPD) to 9,000 by 2021. There are few published audits of neurology services to assist care planning. As a first step towards evaluating future service needs for this group of patients, we audited a single tertiary referral IPD and Other Movement Disorders clinic for 2006. A total of 497 patients from all counties in Ireland were seen; 225 (59%) of patients had IPD, 32 (8.2 %) had atypical parkinsonism, and 22 (5.8%) dystonia. In a subset of 275 patients, 151 (55%) were referred by GPs, 74 (27%) by other consultants, and 49 (18%) by other consultant neurologists. Diagnosis was changed in 22 (38%) and medication was adjusted in 203 (74%). A telephone survey of 50 patients demonstrated 100% satisfaction with the improved access to the clinical nurse specialist, telephone support and improved continuity of care. The IPD and Other Movement Disorders clinic provides an important local, regional, and national diagnostic and therapeutic service for complex movement disorders. It is proposed that a national registry of IPD and audit of the delivery of care to patients with movement disorders is needed.

Introduction

For over 10 years the department of Neurology at the Mater Misericordiae University Hospital (MMUH) runs a once-weekly specialist and multi-disciplinary outpatient clinic for patients with idiopathic Parkinson's disease (IPD) and other movement disorders. The clinic also accepts referrals of patients with atypical forms of dementia. All patients are seen at least once by a consultant neurologist with a specific interest in movement disorders and atypical dementia (TL) and by a movement disorders nurse specialist (BM). Given the paucity of current research into the management of IPD in Ireland, a retrospective audit of this clinic was carried out for the year 2006.

Methods

This audit sought to describe: 1) patient residence in terms of HSE region; 2) clinic activity in terms of the numbers of new and return patient attendances for the 12-month period, and the proportion with treatment changes; 3) diagnostic spectrum; 4) source of patient referral. We used the MMUH information center together with the department of neurology secretarial database and appointments diary to provide details of numbers of new and return visits to the movement disorders clinic, and of HSE region of residence. A disease profile was established by accessing the clinic database for up-to-date communication between the consultant neurologist (TL) and the patient's general practitioner. Patients with typical and atypical parkinsonism were identified by obtaining a specific list maintained the movement disorders nurse specialist (BM). In order to obtain information regarding source of referral and change in treatment and diagnosis, a sub-review of 275 individual patient charts was undertaken (TL, EC).

Results

HSE Region and Referral Source

A total of 497 patients were seen in 2006. All except three were domiciled within the eight HSE regions, with the majority (59%) within the Eastern HSE region. Other HSE regions were represented as follows: North-Western (3.8%), North-Eastern (14.5%), Western (2.8%), Midland (6.8%), South-Eastern (5.8%), Southern (1.6%), Mid-Western (5%). Referral data were available for a subset of 275 patients via chart review. The majority of this subset were referred by a general practitioner (55%), with the remainder referred by a consultant physician or surgeon (27%) or a consultant neurologist (18%). There were two patients referred from Northern Ireland and one patient referred from Great Britain.

Clinic Activity

A total of 670 patient attendances took place in 2006. Almost one third (220 attendances, 32.8%) were patients attending the clinic for the first time. Of the remaining 450 attendances, the great majority (411 attendances, 91%) were patients returning for follow-up having previously been seen in the clinic prior to 2006. A comparatively small fraction (39 attendances) were patients returning for follow-up having previously been seen in the clinic earlier in 2006. The sub-review of 275 patients indicated that 38% of patients had their diagnosis changed and 74% of patients had their treatment changed following attendance at the clinic.

Diagnostic Spectrum

The commonest diagnosis was IPD in 225 patients (59%). The remaining patients were diagnosed with a range of other movement disorders and dementias (Table 1). Specialist clinics are inevitably subject to referral bias; this is illustrated by the presence of 53 patients with young-onset IPD (onset at age < 45 years) in this audit (23.5 % of IPD cases). For comparison, the percentages of patients with movement disorders from the combined databases of the movement disorder clinics at Columbia University Medical Centre (New York City) and Baylor College of Medicine (Houston) are given in parentheses and marked US in table 1. Overall, the Irish and American figures are remarkably similar, except more patients were seen at the MMUH with parkinsonism and more patients were seen with dystonia in the US.

Discussion

Expert groups recommend referral of patients with movement disorders to specialist centres¹ to assist in the differential diagnosis as this may be difficult. We found 45% of patients were referred by consultants of whom 18% were other neurologists requesting a further opinion in relation to diagnosis or management.

Also, the availability of a speech and language therapist, physiotherapist and movement disorders nurse specialist allows a multi-disciplinary approach to patient care including the provision of a separate nurse-led clinic for selected patients. Our specialist IPD and movement disorder / atypical dementia outpatient service delivers a number of elements which do not form part of a standard outpatient service, and this has resource implications. For example, clinical rating scales² are very useful for monitoring the evolution of clinical syndromes such as parkinsonism, and are routinely performed at our clinic. In addition, the use of video recordings for unusual clinical syndromes form a permanent part of the patient's hospital record and are stored in a secure format. Other opinions can be sought as video recordings are reviewed together with other specialist Dublin-based clinicians at the monthly movement disorders video meeting at the Dublin Neurological Institute (DNI) at the MMUH. This meeting forms part of the diagnostic evaluation for difficult cases, and also has an important role in the teaching of neurologists in training. It is planned that international experts will participate at this meeting via standard videolink technology. Research registrars routinely attend this clinic, and collect patient data for use in MMUH ethics committee- approved research projects, e.g. the genetics of young-onset IPD in Ireland.

By extrapolating from the UK prevalence rates, there are at least 5,500 patients with IPD in Ireland.⁵ This figure will substantially increase over the next two decades as the population ages, with significant implications for service delivery. At present, approximately 35 weekly movement disorder clinics are held at the MMUH per annum; given that the 2006 figure of 670 attendances per annum is representative, overbooking is routine. Given the extensive assessment outlined above, patients with movement disorders require extra time to assess and treat per patient. Overbooking leads to long clinics and consequent difficulties for this disabled group of patients who, as this audit shows, have often travelled long distances to be seen.

An important related aspect of service delivery for selected patients with IPD, tremor, and dystonia is the provision of deep brain stimulation (DBS) which is not currently available in Ireland. This functional neurosurgical technique involves the implantation of electrical stimulators into the basal ganglia with follow-up in a specialist clinic for

adjustment of the stimulator parameters, and is now standard-of-care for selected patients. A total of 151 patients from Ireland have had DBS performed in the UK between 2003-2008 via the HSE overseas treatment scheme, and a further three patients have had the procedure in Ireland as part of a collaboration between the DNI and the Mater Private Hospital. Therefore, an independent DBS clinic was set up at the DNI in 2009. This clinic accepts referrals from all over Ireland for pre-operative assessment to determine if patients are suitable for DBS, and also provides post-operative follow-up and adjustment of the stimulation for patients who have had DBS. Seventy-five patients have been assessed at the DNI DBS clinic since its inception. Since 2006, a further four consultant neurologists with a special interest in movement disorders have been appointed in Ireland. Given the anticipated increase in demand for specialist movement disorder services, including the difficulties of managing patients who have had DBS elsewhere, there is a strong case for a national audit of the delivery of care to patients with movement disorders and the provision of a national DBS service.

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