General practice referrals to a department of neurology

ABSTRACT—Objective: Assessment of general practitioner (GP) new referrals to a neurology department in terms of satisfaction for patient and doctor.

Design: Prospective study by questionnaire of patients, GPs and specialists.

Setting: Neurology hospital outpatient clinics.

Subjects: 339 consecutive new outpatients.

Main outcome measures: Overall patient satisfaction with clinic attendance, with allocated time and waiting times after referral; GPs' reasons for referral, and satisfaction with outcome; specialists' actions in the clinic, views on referral.

Results: Some 67% of patients found the referral helpful; 23% felt there was insufficient time to explain fully their problem. Nearly half of the patients had waited ≥6 months for an appointment. The GP was uncertain about the diagnosis and referral in 76% of cases. Specialists made a new diagnosis in 40% of referrals, discharged 73% (with or without investigation) and admitted 11%; 76% of referrals were felt to be appropriate.

Conclusions: Patients and GPs usually found the referral helpful. Seeing patients more briefly is inappropriate since almost a third already felt consultation time to be short. Although some referrals may have been inappropriate, the dominant deficiency in the service was the time they had to wait after the referral. To satisfy local need, it is estimated that twice the present number of consultant neurologists would be required.

Methods

All patients referred by letter for a new appointment at neurology outpatient clinics between 31 March 1994 and 14 July 1994 (15 weeks) were identified. The GP was sent a questionnaire about reasons for referral, supposed diagnosis, presence of inappropriate or exaggerated behaviour, pressure to refer and degree of urgency; this questionnaire was sent when the outpatient appointment was sent to the patient. After the relevant clinic, the specialist completed a questionnaire on action taken in the clinic, follow-up, diagnosis and investigation, appropriateness of prioritisation, presence of inappropriate or exaggerated behaviour and appropriateness of referral. The specialist's letter to the GP was accompanied by a second questionnaire enquiring about the referral-to-consultation delay, the quality of information received, whether other facilities might have obviated the need for referral and how useful the referral was overall. Some days after the clinic the patient was sent a questionnaire, enquiring about expectations of the referral, whether the visit was helpful and explanations were satisfactory, whether enough time was allowed and whether overall the referral was felt to be necessary. Questionnaires were returned to the University Hospital of Wales audit department, anonymised and coded. Practice sizes for the county of South Glamorgan were provided by the Family Health Services Authority.

Results

Of 530 clinic NHS referral letters logged, 109 were from other hospital specialists; of 421 GP referrals, 15 patients cancelled and 35 patients who had been expected did not attend; 32 others were non-attenders who either cancelled their appointment before the final clinic lists were compiled or changed appointments to times outside the span of the study. Of the 339 patients who attended the clinic, 56% were women; the median age of all referred patients was 43.3 years (interquartile range 24 years). Questionnaires for these 339 were completed by all the hospital specialists, by 69% and 70% of GPs before and after the clinic visit respectively, and by 75% of patients; all four questionnaires were available in 46% of cases. For the county of South Glamorgan the annual referral rate per 1000 population was calculated to vary between the 47 practices from 0.3 to 3.8 with a mean of 1.9 (95% CI 1.7–2.2).

The GP was only certain about the diagnosis in 24% of referrals and lack of a firm diagnosis was the main

C M WILES, PhD, FRCP, Professor of Neurology, University of Wales College of Medicine, Cardiff
M LINDSAY, MRCP, Audit Facilitator, South Glamorgan Medical Audit Advisory Group, General Practitioner, Grangetown, Cardiff
reason for referral given by the majority of GPs (Table 1); in 51% of referrals the GP did not feel particularly pressurised by the patients for referral.

For patients, the main purpose of the referral was to find out what was wrong (63%), to be sure nothing was seriously wrong (43%) and/or to discuss ways of getting better (45%). Some 6% of patients were given less than a week’s notice of an appointment; 59% had 1–4 weeks notice, and 19% had more than four weeks notice (15% of data were missing). For the 328 patients for whom accurate data were available, the delay from referral to consultation was 4 weeks or less in 10%, 5 to 26 weeks in 43%, 27 to 52 weeks in 33%, 1 to 2 years in 5% and over 2 years in 9%. The overall median waiting time was 23 weeks (interquartile range 28 weeks, range 0–177 weeks). GPs thought that the delay had been reasonable in only 52% of the 70% of patients for whom they returned questionnaires.

At the clinic, patients were seen by a consultant (73%), a senior registrar (18%) or registrar (substantive or honorary); it was exceptional for a patient to see only a senior house officer. The specialists’ diagnoses were classified in the same way as in the audit study by the Association of British Neurologists in 1992 [1] where 16 diagnostic groupings were found to encompass 74% of the new referrals (Table 2); they

| Reason given by GPs for referral to specialist | % |
|---------------------------------------------|---|
| Consultant diagnosis                        | 69 |
| Specific investigation                      | 24 |
| Advice on management                        | 46 |
| Specific non-operative Rx                   | 5  |
| To reassure GP                              | 14 |
| To reassure patient                         | 27 |
| At insistence of patient                    | 9  |
| At insistence of relative                   | 4  |
| To give GP a ‘rest’                         | 3  |
| To avoid legal problem                      | 3  |
| Overview of the case                        | 12 |
| Suggested by other doctor                   | 5  |

| Diagnosis                                      | Cardiff % (n=339) cumulative % | UK % (n=1620) cumulative % |
|------------------------------------------------|---------------------------------|----------------------------|
| Epilepsy                                       | 15.0                            | 12.6                       |
| Headache (not migraine)                       | 7.7                             | 9.0                        |
| Migraine                                       | 10.3                            | 8.3                        |
| Stroke                                         | 1.5                             | 6.7                        |
| Faint/collapse                                 | 2.7                             | 5.0                        |
| Cervical disc disease                         | 4.7                             | 4.3                        |
| Peripheral nerve lesion                       | 5.6                             | 3.9                        |
| Transient ischaemic attack                    | 1.5                             | 3.6                        |
| Multiple sclerosis (possible/probable)        | 5.9                             | 3.2                        |
| Multiple sclerosis (definite)                 | 4.1                             |                            |
| Dizziness                                      | 5.0                             |                            |
| Parkinsonism                                   | 3.5                             |                            |
| Lumbosacral disc disease                      | 2.4                             |                            |
| Cranial nerve lesion                          | 3.8                             |                            |
| Peripheral neuropathy                         | 2.1                             |                            |
| Facial pain                                    | 0                               |                            |
| Dementia                                       | 1.2                             |                            |
| Non-organic                                    | 8.2                             |                            |
| Other                                          | 13.6                            |                            |
| Uncertain                                      | 1.2                             |                            |

For patients, the main purpose of the referral was to find out what was wrong (63%), to be sure nothing was seriously wrong (43%) and/or to discuss ways of getting better (45%). Some 6% of patients were given less than a week’s notice of an appointment; 59% had 1–4 weeks notice, and 19% had more than four weeks notice (15% of data were missing). For the 328 patients for whom accurate data were available, the delay from referral to consultation was 4 weeks or less in 10%, 5 to 26 weeks in 43%, 27 to 52 weeks in 33%, 1 to 2 years in 5% and over 2 years in 9%. The overall median waiting time was 23 weeks (interquartile range 28 weeks, range 0–177 weeks). GPs thought that the delay had been reasonable in only 52% of the 70% of patients for whom they returned questionnaires.

At the clinic, patients were seen by a consultant (73%), a senior registrar (18%) or registrar (substantive or honorary); it was exceptional for a patient to see only a senior house officer. The specialists’ diagnoses were classified in the same way as in the audit study by the Association of British Neurologists in 1992 [1] where 16 diagnostic groupings were found to encompass 74% of the new referrals (Table 2); they
followed a similar pattern with the exception of a rather low frequency of stroke and transient ischaemic attack. In 40% of patients, specialists made a new diagnosis which had not explicitly been made by the GP, while in 33% the diagnosis was already known; in 21% the diagnosis was uncertain. The specialist made new recommendations on management in 45% of patients and essentially reinforced the actions that the GP was already taking in 23%. In 25% of patients the specialist felt that there was an element of exaggerated or inappropriate behaviour; and this was thought possibly or definitely to be the case in 26% by the referring GP. Actions taken by the consultants in the clinic are summarised in Table 3. Decisions varied between consultants, but there was general uniformity in proportions of patients discharged or admitted after the first consultation. Compared to the larger UK neurology audit, slightly more patients were discharged after the initial consultation, fewer were followed up, but a similar proportion were admitted for further investigation or treatment.

Consultants gave GPs' letters a priority of 'soon' or 'urgent' in 41% of cases and 'routine' in 58%; having seen the patient they considered their own priority incorrect in 9% of cases and the priority given by the referring doctor inappropriate in 15% of cases. After the consultation, the specialist considered the referral possibly or definitely inappropriate in 23% of cases: reasons for this were that the GP should have made the diagnosis (8%); the GP should have treated the problem (8%); the problem had gone away but the appointment had not been cancelled (3%); the patient had already been seen by another consultant and a second opinion was not specifically being requested (3%) or the patient had been referred to the wrong specialty (2%).

Patients were asked whether they had been helped by seeing the specialist: 46% felt that they had definitely been helped and 21% had probably been helped; 68% were satisfied or very satisfied with the explanation of their problems and the proportion was not significantly influenced by whether they saw a consultant or not. However, 11% felt they had had insufficient time and 12% only 'nearly' enough time to explain the problem to the specialist. There was an association between this perception and perceived 'inappropriate' or 'exaggerated' behaviour by both specialists and GPs (chi squared 38.7, p<0.001). Furthermore, patients who were thought by the specialist to be 'exaggerating' or 'inappropriate' were less likely (chi squared 30.8, p<0.001) to feel that they had been helped by the consultation. Ten per cent of patients subsequently felt that the GP could probably have managed without making the referral. Nineteen patients (7.5%) remarked on the lack of information on investigations or treatment, 13 (5%) made a specific comment about the lack of a firm diagnosis, four (1.6%) found the clinic doctor unpleasant and two commented about seeing a trainee. Although 89% of patients felt that the specialist had a reasonable grasp of their problem, a third felt that it might have been helpful to discuss the matter further with a specialist nurse after seeing the doctor. Fifteen (6%) patients commented on long in-clinic waiting times and five (2%) on short waiting times.

GPs expressed general satisfaction with the 'help' from the consultation and the content of the clinic letter. One GP reported not receiving any letter, two found the content completely unhelpful and 15 (7%) 'rather unhelpful'. Comments were made on the unacceptable length of wait for an appointment in 18 (8%) of cases or for subsequent investigation (MRI scan) in two cases, the failure to comment on specific questions in the referral letter (three occasions), confusion in the light of previous correspondence (two occasions) and inadequate explanation of the diagnosis (once). Retrospectively, GPs felt that they probably could not have managed without referral (70%), were uncertain in 13% of cases, and felt that they might have managed without in 16%; making a new diagnosis or giving specific advice on management was not statistically associated with this uncertainty about the referral. Although there was some association between patient satisfaction and that of the referring practitioner, it was notable that about 30% of patients whose GP had expressed satisfaction, in fact stated that they were 'barely satisfied' or 'not satisfied' with the explanation given for their condition.

| Table 3. Actions taken by consultants in outpatient clinics |
|-----------------|----------|----------|
| Investigations: | %        | cumulative %  |
| Blood test    | 35       |          |
| MRI           | 9        |          |
| CT            | 15       |          |
| Xray          | 9        |          |
| EEG           | 11       |          |
| EMG/NCS       | 4        |          |
| Evoked potentials | 1      |          |
| Decisions:    |          |          |
| Discharge without investigation | 38 |          |
| Discharge with investigation | 34 | 73 | 61 |
| Follow-up only | 1        |          |
| Investigate and follow up | 13 | 14 | 29 |
| Admit (waiting list) | 7        |          |
| Admit (urgent)  | 3        | 10       |
| Treat / discharge | 1        |          |
| Refer to other specialty | 3        |          |
Discussion

The aim of this study was to gain numerical evidence about outpatient neurology practice in a part of the UK where resources in terms of whole time equivalent consultant neurologists are low. The study was, to some extent, modelled on that by Roland et al [2] in respect of orthopaedic outpatient referral practice, where doctor and patient satisfaction were studied and appropriateness of referral was assessed.

During the 15 weeks of the study we estimated that around 100 patients had been referred by GPs for private consultations with local neurologists (personal communication): no detailed information is available about diagnosis or satisfaction of these consultations, but this group represents 23% of all GP referrals in the ascertainment period and the diagnostic case mix might differ as this group had a shorter waiting time. It is likely that the NHS patients referred plus those seen in private practice by local consultants represent the majority of referrals to neurologists from Gwent and Mid and South Glamorgan. However, patients referred in this study do not provide a fully representative view of all neurological disease. In the UK, many patients, particularly those with stroke, transient ischaemic attack (TIA), dementia and acute neurological disorders are not initially referred to neurologists. Stroke/TIA patients were even less well represented in the present series than in the UK audit of neurological referrals, probably on account of the length of the waiting time.

In the orthopaedic study by Roland and colleagues [2], GPs were certain about the diagnosis in 53% of cases compared with 24% in our study. The requirement for unambiguous ‘consultant diagnosis’ was noted in 69% in our study and this need was also reflected by the expectations of the patients in wanting to find out ‘what was wrong’. In only about 5% of cases did the GP feel that referral was probably unnecessary; direct access to hospital investigations, eg computed tomography (CT) scanning, was sometimes quoted as a cause for this. The fact that the GP perceived no particular patient pressure for referral in 51% of referrals and that 30% of patients whose GP was satisfied with the consultation process were not themselves satisfied, raises the possibility that some patients may have been unclear in their own minds about the need for a ‘neurological’ referral. A disjunction in expectation between specialist and patients may easily arise in the clinic if patients are unclear why they are being referred or if the GP referral is perceived by the hospital staff to be inappropriate (rightly or wrongly). Specialists felt that the referral had been inappropriate in 23% of cases (43% in the study of orthopaedic practice [11]). In a study of avoidable referrals in a general practice in Cardiff [3], 58 out of 110 hospital referrals (to all specialties) from a single practice were considered ‘avoidable’, 32 of these being primarily due to lack of resources; 11% of those whose referral was for ‘specialist skills or procedure’ were considered avoidable. In our study, because of the length of the waiting list, referrals that might initially have been appropriate may not have been by the time of the clinic visit. There was a tenfold variation in referral rate between the 47 general practices of South Glamorgan included in the study, although referral figures per practice are small and confidence in their accuracy on an individual practice basis must therefore be low. In a recent study [4] the ‘inappropriate’ referral rate from GPs to specialists was 9.6%, though there was a marked excess of this category among orthopaedic referrals. In that study, variations in referral rates between GPs could not be accounted for by ‘inappropriate’ referrals, and the application of referral guidelines would have been unlikely to reduce referrals. The wide range of symptomatology associated with neurological disease, and the lack of diagnosis in most cases at referral, probably make general application of guidelines impractical.

The waiting time from referral to consultation was clearly unsatisfactory and compares poorly with the national audit figures for neurology [1] in which 62% of all NHS outpatient referrals were seen within ten weeks. Although the comparison is not exact, approximately 29% of GP referrals in our study were seen within that time while 47% waited for more than 6 months. The importance of outpatient waiting times, well recognised by most doctors, has recently attracted greater attention [5] and has become a feature of the ‘Patient’s Charter’. Waiting time for new patients can be reduced by seeing more patients per clinic, increasing the number of clinics per specialist, increasing the number of specialists, altering the ratio of new to follow-up cases seen and/or by increasing the number seen by trainees. The last is scarcely a credible response to a referral made by a GP who often has more experience than the trainee. Consultation times per patient recommended by the Association of British Neurologists [6] are about half an hour per new case for a consultant (in the absence of students or the requirement for close supervision of trainees) and 40 minutes for a trainee. Consultation time in private practice is perhaps the appropriate yardstick for comparison. In the current study, the consultation rate per clinic approximates to the above recommendations. The total number of weekly clinics undertaken by each consultant in the study falls well within the recommended number of weekly clinics for a consultant. The ratio of new to follow-up cases in general neurology clinics at University Hospital of Wales was 1:1.53 in 1995. Our follow-up rate is probably low by comparison with other units, the national audit of referrals and other specialties, and any further reduction would be likely to disadvantage patients with serious chronic neurological disorders. An increase in specialist availability and sessions is the most plausible way to reduce the waiting list. An editorial in 1981 [7] commented on the low ratio of neurologists to population in the
UK (then approximately 1/360,000) compared with the USA (approximately 1/41,000), and a ratio of 1/200,000 has been a target of the Association of British Neurologists for some years: recently a target ratio of 1/100,000 has been suggested (DL Stevens, personal communication) as representing the number of neurologists needed for most or all patients with neurological symptoms to be seen. In 1993 there were 227 consultant neurologists in England and Wales [8] giving a ratio of about 1/225,890 persons (rather than whole time equivalents). By current guidelines, the number of neurologists working for the population under study should thus be about six, or double the number at the time of this study.

Although over two-thirds of patients were satisfied or very satisfied with their consultation, a significant minority felt that they had not really had enough time to explain their problems. In a previous study [9] of referrals of headache to neurologists, about a third were dissatisfied with the consultation. As in the current study, it made no difference whether patients were seen by a trainee nor whether or not they were investigated further. The main feature associated with satisfaction appeared to be the time spent in analysis of the problem and discussion, particularly where the diagnosis (eg migraine) was not in doubt and the patient was seeking advice on management. There was an association between patients' perceived lack of time for explanation and the belief by the specialist that there were elements of exaggerated or inappropriate illness behaviour or the specialist made a 'non-organic' diagnosis. Patients with 'hard' diagnoses were less likely to have felt pressed for time. Clearly there may be little correlation between the time required for specialists to arrive at a formulation of the medical problem and that required by patients to feel satisfied that they have absorbed such a formulation even if they accept it. Part of the problem lies in the fact that it is far easier to assign a diagnostic label and expound specific treatments than to understand and explain why a particular patient should be suffering from a symptom complex such as tension headache. Nevertheless, attempts to rush patients or to override their need to discuss their symptoms may well be a major factor in communication breakdown, dissatisfaction with the consultation, complaints and ultimately legal action [10]. Although direct comparison is difficult, one study [11] found that neurologists processed new outpatients with neurological symptoms more efficiently than general physicians as judged by fewer uncertain diagnoses, investigations, prescriptions and follow-up visits.

The present study has brought to light that most patients and GPs are in fact satisfied with referrals to a neurology clinic, but a minority are not. The waiting list time emerges repeatedly as a key factor in satisfaction of both patients and GPs. Given that attempting to modify general practice referral patterns is unlikely to contribute significantly to the solution of this problem and that it is unclear how such modifications could be brought about, a higher specialist consultation rate must be achieved. We argue that an increase in the number of consultant specialists is the only plausible route for this, since the alternative—shorter consultation times—increases levels of patient dissatisfaction. Better patient satisfaction might be more likely if the GP explained to the patient what can reasonably be expected from referral. For this to be achieved, there needs to be more interaction and educational activity between specialists and their general practice colleagues. For patients with specific diagnoses, eg epilepsy, Parkinson's disease and multiple sclerosis, clinical nurse specialists may improve appointment satisfaction, although this will be more evident at follow-up than at the first appointment when accurate diagnosis is required. With symptom complexes of less clear causation, the specialist probably needs to spend more time explaining the nature of the problem to the patient.

Acknowledgements

We are grateful to Bernadette Dickinson and Rachel Friel (University Hospital of Wales audit staff) and Sarah Evans (South Glamorgan Medical Advisory Audit Group), David Prichard (neurology co-ordinator), and the neurology department secretaries for help in carrying out this study. We thank all the patients, general practitioners and neurology department staff. We are grateful to Dr J Graham and Dr INF McQueen for their participation and for comments on the manuscript.

Note added in proof: a further (fourth) consultant neurologist has been appointed since this manuscript was accepted for publication.

References

1 Association of British Neurologists and the Research Unit of the Royal College of Physicians. UK national audit of care of common neurological disorders, 1992. Summary available from the Association of British Neurologists, 9 Fitzroy Square, London W1P 5AH.
2 Roland MO, Porter RW, Matthews JG, Redden JF, et al. Improving care: a study of orthopaedic outpatient referrals. Br Med J 1991;302:1124-8.
3 Elwyn GJ, Scott NCH. Avoidable referrals? Analysis of 170 consecutive referrals to secondary care. Br Med J 1994;309:576-8.
4 Fertig A, Roland M, King H, Moore T. Understanding variation in rates of referral among general practitioners: are inappropriate referrals important and would guidelines help to reduce rates? Br Med J 1993;307:1467-70.
5 Smith T. Waiting times: monitoring the post referral wait. Br Med J 1994;309:593-6.
6 Association of British Neurologists. Good neurological practice with particular reference to job plans for consultant neurologists in the UK, 1993. Available from the Association of British Neurologists, 9 Fitzroy Square, London W1P 5AH.
7 Marsden CD. What should neurologists do? J Neurol Neurosurg Psychiat 1981;44:1059-61.
General practice referrals to a department of neurology

8 Wilson R, Allen P. Medical and dental staffing prospects in the NHS in England and Wales 1993. Health Trends 1994;26:70-9.
9 Fitzpatrick R, Hopkins A. Referrals to neurologists for headaches not due to structural disease. J Neurol Neurosurgery Psych 1981;44:1061-7.
10 Levinson W. Physician-patient communication: a key to malpractice prevention. JAMA 1994;272:1619-20.

11 Patterson VH, Esmonde TFG. Comparison of the handling of neurological outpatient referrals by general physicians and a neurologist. J Neurol Neurosurgery Psych 1993;56:830.

Address for correspondence: Professor C M Wiles, Department of Medicine (Neurology), University of Wales College of Medicine, Cardiff, South Glamorgan CF4 4XN.

---

Measuring Outcomes in Rheumatoid Arthritis

Edited by Andrew F Long and David L Scott

The increasing emphasis on evidence-based medicine requires treatment and provision of services to be based on sound evidence of effectiveness. Clinicians should monitor the extent to which their treatment plan is working and desired outcomes are being achieved.

Assessment and monitoring of outcomes for a chronic disease such as rheumatoid arthritis, with its multiple stages, variable course and often inexorable progression poses particular difficulties. The answers are important to a range of interested parties — patients, carers, primary care givers, rheumatologists, other members of the clinical care team, policy makers, research workers and commissioners of health services. Each has an individual perspective and they may give priority to different outcomes.

This book provides a comprehensive overview of how to assess the outcomes of rheumatoid arthritis care. It provides insight into the different perspectives of researcher, patient and clinician. It tells how to search the literature on measurement of outcome and evidence of effectiveness, placing special emphasis on measurement of functional status, handicap and combined measures. It will prove an essential source of information to all involved in the treatment and care of patients with rheumatoid arthritis, to health commissioners and health care researchers.

CONTENTS — Introduction ◆ Exploring outcomes: approaches and key issues ◆ Searching the literature ◆ A methodological perspective ◆ The rheumatologist’s perspective ◆ A patient’s perspective ◆ An overview of studies of disease outcome ◆ Measuring impairment ◆ Measuring functional status ◆ Measuring handicap ◆ Combined measures and practical issues ◆ Issues of data collection ◆ Conclusions and future developments

Price £10.50 (including p&p), £12.00 overseas
ISBN 1 86016 032 8. Softcover, 104 pages

ROYAL COLLEGE OF PHYSICIANS

Journal of the Royal College of Physicians of London Vol. 30 No. 5 September/October 1996