A B S T R A C T

A prospective study was performed on elective neurosurgical office referrals to one neurosurgeon at the Toronto Hospital from September 1988 to May 1996. Patient level of information was tested using the chi-square test on the study population of 2,017 patients grouped according to the type of referring doctor and regional category of diagnosis.

There was a statistically significant difference in the degree of knowledge of referred patients according to the type of referring doctor ($p < 0.008$). In addition there was statistical significance found in the difference in degree of knowledge among patients referred with the various regional categories of disease ($p < 0.008$).

Patients referred by family physicians are not as informed as to the nature of their neurosurgical referral as those referred by neurologists and other specialists. Furthermore, patients with an intracranial diagnosis had a greater level of knowledge about their referral than those patients referred for spinal, peripheral nerve or other diagnoses.

A B R É G É

On a effectué une étude prospective sur les patients envoyés pour neurochirurgie élective au cabinet d'un neurochirurgien de l'hôpital de Toronto entre septembre 1988 et mai 1996. Le niveau d'information du patient a été étudié à l'aide du test chi-carré sur une population de 2 017 patients regroupés en fonction du médecin traitant et de la catégorie régionale du diagnostic.

On a observé une différence statistiquement significative dans le niveau de connaissances des patients en fonction du type de médecin traitant ($p < 0,008$). On a également relevé un lien statistique significatif dans le niveau de connaissances des patients par rapport aux diverses catégories régionales de maladie ($p < 0,008$).

Les patients envoyés par des médecins de famille ne sont pas aussi bien informés des raisons de leur orientation vers un neurochirurgien que ceux envoyés par des neurologues et d'autres spécialistes.

En outre, les patients chez qui on a diagnostiqué un trouble intracrânien connaissent mieux les raisons de leur orientation vers une neurochirurgie que ceux envoyés en raison d'un problème au niveau des nerfs périphériques rachidiens ou autres.

Elective Neurosurgical Office Consultations: How Well Are Patients Informed?

Joseph Bampoe, MB ChB, FRCSC, Bodour Salhia, Johann Micallef, Jennifer Glen, Mark Bernstein, MD, FRCSC

The everyday event of medical referrals has been called a "surprisingly complex act."¹ The referral system was originally developed in the United Kingdom and became well established in 1948 when the National Health Service nationalized the hospitals and institutionalized the distinction between specialists and family physicians (FPs).² Quantitative and qualitative research has been carried out in an attempt to explain this complex act but many questions remain unanswered. The issue of referrals to a specific specialty has not been adequately addressed by previous workers but could perhaps contribute to an understanding of the referral process in general. This study was performed to study the level of information of patients referred to one neurosurgeon and is thus specialty specific.

METHODS

The main source of data for this study was information obtained prospectively by one neurosurgeon, the senior author. This consisted of the type of referring doctor, whether the patient knew why he/she was being referred, and whether the patient knew what type of doctor he/she was seeing. These data were recorded by the senior author after a short interview before each consultation during the study period and were subsequently categorized. The information was kept apart from the office

notes over the 92-month duration of the study. At the end of this period, the review was performed on the study population of 2,017 consecutive elective consultations seen in the office of one neurosurgeon.

Patients were eligible for the study if they could communicate in English and if they did not have a physical or cognitive problem that impaired them from responding. Patients were grouped by referring doctor (FP, neurosurgeon, neurologist, and all other specialists) and then by regional category of diagnosis (brain, spine, peripheral nerve, and other). Patients seen in consultation in the emergency room, the inpatient ward, or in the specialty clinic (neuro-oncology) of the specific neurosurgeon were excluded.

Referred patients were classified as not informed if they did not know the purpose of their referral and the specialty of the consultant (neurosurgeon). Patients were classified as partially informed if they were knowledgeable of only one of the above-mentioned components. They were fully informed if they were aware of both the purpose of their visit and the specialty of the consultant. The chi-square test of statistical significance was used on the non-parametric data compiled. Using Microsoft Excel 5.0 (Microsoft Corporation, Redmond, WA), the data were sorted and correlated. Patient level of knowledge was analyzed separately with respect to referring doctor and diagnosis.

RESULTS

Of the total 2,017 patients reviewed, 1,050 (52%) were referred by FPs and 967 (48%) were referred by specialists (Figure 1). It was found that 1,252 (62%) of all patients were fully informed, 713 (35%)

Division of Neurosurgery, The Toronto Hospital Western Division, University of Toronto, Toronto, Ontario

Correspondence and reprint requests: Dr. Mark Bernstein, The Toronto Hospital Western Division, Suite 2-405, McLaughlin Pavilion, 399 Bathurst Street, Toronto, ON, M5T 2S8, Tel: 416-603-6499, Fax: 416-603-5298, E-mail: mbernstein@torhosp.toronto.on.ca

were partially informed, and 52 (3%) were not informed. There was a statistically significant difference in the degree of knowledge among patients referred by FPs and neurosurgeons ($p=0.001$); FPs and neurologists ($p=0.002$); FPs and other specialists ($p=0.004$). From the data it was deduced that patients referred by FPs were not as informed as those referred by specialists (Figure 2). The degree of knowledge with respect to regional category of diagnosis also resulted in a statistically significant difference; brain and spine ($p=2.620 \times 10^{-15}$); brain and peripheral nerve ($p=7.954 \times 10^{-11}$); brain and other ($p=0.000$). Patients with intracranial diagnoses were more informed about the nature of their neurosurgical referral than those patients diagnosed with spinal, peripheral nerve or other diagnoses (Figure 3).

DISCUSSION

The referral process is usually undertaken for one of the following reasons:³

- 1) Diagnosis (and treatment where appropriate),
- 2) Treatment of an already diagnosed condition,
- 3) Reassurance of one of the parties involved (patient, relative or the referring doctor), or
- 4) Investigation which the referring doctor can only order through the consultant being referred to.

The importance of the referral process has led to its examination by several investigators.^{1,2,4-6} A reason for this interest is the realization that the success or failure of referrals has relevant implications on the efficient utilization of health care resources and the continuing education of health care providers and their patients.

Why are patients not fully informed?

The referral process is not part of the formal medical curriculum nor does it appear as a continuing medical education topic.¹ The decision to refer a patient or to seek medical consultation has traditionally been made independently by the physician treating a patient. It could be argued that only the health care practitioner at whatever level knows the intended reason for the referral.⁶

It has been estimated, however, that patients initiate, at one level or another, about half of all referrals.⁷ Patients may also be called upon to play a more crucial role in certain clinical settings. Muzzin notes in her study of certain southern Ontario practices that for about 90% of referrals that are considered routine, there is no direct communication between physicians, probably because of the trust of referring physicians in consultants and because of time constraints.^{8,9}

Physicians may simply forget to inform their patients of what may seem obvious and instead concentrate on assuring them that they will be in good hands with their consultants, particularly since the trust level of most patients is so high.

In a comprehensive longitudinal study of the referral process in central Canada, Muzzin found that patients were very selective about what they shared with their referring physicians and similarly referring physicians were selective about what they shared with their patients.¹⁰ In another study in England which examined the perceptions of patients, family practitioners, and consultants involved in referrals in order to assess the extent of agreement between these parties on the reasons for referrals, only a 49% overall agreement on the reason for referral was found between family practitioners and patients.³ A possible underlying reason for these disagreements could be the use of referral by some family practitioners as a solution to the problem of the patient with overt or covert demands for reassurance.³

Patients with difficult chronic problems with several referrals over a prolonged period of time might also lose interest in whom they are seeing and why after being referred to yet another specialist.⁵

Our findings of a lack of complete information in 38% of patients referred for an office consultation to a single neurosurgeon as to who they were seeing and/or why might be explained by some of the above noted phenomena.

Why are there differences between physicians (FPs and specialists)?

The accumulated knowledge of patients of the nature of their complaints would probably be greater after a second visit to a

physician than after the first. This probably explains to some extent the significant differences in patient degree of information noted between patients referred from specialists (secondary or tertiary care physicians), and those referred by family practitioners (primary care physicians).

In the study by Grace et al. on the perceptions of patients, general practitioners and consultants about the necessity and suitability of referral, the best agreement was found between patient and specialist and the worst between patient and general practitioner.⁶ Muzzin also noticed that many patients in her study expressed a distrust of their physicians, possibly more at the family physician level than at the specialist level.⁵ However, Muzzin's study population of 50 referrals were not randomly selected and hence not statistically representative. There is a suggestion from these findings however, that specialists are better communicators with patients possibly because of patients' perceptions of the specialist as having more expertise in dealing with their problems.

A possible underlying reason for the lack of adequate communication between family practitioners and their patients is the noted reluctance of several family practitioners to volunteer their opinions of diagnoses and suggested plan of management to specialists on referral of their patients.⁴ This could, however, also indicate the confidence of the family practitioners in specialists to adequately deal with these problems.⁹

Why does the diagnosis make a difference?

In a study of referral rates and practitioner levels of diagnostic certainty in an urban family practice, Calman and his colleagues found a low correlation between the degree of diagnostic certainty by the primary care practitioner and the specificity of requests made on referral to consultants for either investigation or treatment.¹¹ There is, however, some evidence that when physicians are certain of their diagnoses and plans of action, their patients are more knowledgeable of these aspects of their management.^{4,12} The significant differences in degree of knowledge found between patients with intracranial disease and patients with other neurosurgical conditions could probably be explained

by the fact that most intracranial diseases have the capacity to be life threatening. Patients would probably be more inclined to take a more active role in their management if they were in this category than if they were in the other groups represented in our study. Another factor might be the obvious association between the concept of a brain surgeon and the brain, whereas some patients might associate the care of spine and nerve problems with other specialists (e.g., orthopedic surgeon). An additional explanation is likely related to the shorter interval between referral and consultation for patients with intracranial problems as opposed to spinal or nerve problems, and therefore less passage of time in which to forget information imparted by the referring doctor.

Value of this study

The familiarity of patients with the nature of their diagnosis and their possible outcome might alter their compliance with their physicians' recommendations. In a study in Taiwan, Wu and his colleagues found that patients' beliefs that their referral was unnecessary was an important cause of referral failures, second only to administrative factors.² Failure to comply with physicians' recommendations could have serious implications on the quality of patient care delivered by health care practitioners. The potential for detrimental effects on patient care is probably more applicable to the complex tertiary health care situation which requires a greater degree of investigation and coordination of information between physicians for a satisfactory outcome in patient management.

The cost to patients of inadequate information on the nature of their complaints can be considerable, some patients going to extreme lengths to obtain a second and, they hope, more favourable opinion.^{6,8}

Lastly, successful referrals facilitate efficient utilization of health care resources.^{2,4,12} Issues such as duplication of tests which in some cases might be harmful to the patient, or the utilization of referrals for reassurance, have not been adequately studied but have the potential to significantly influence health care costs.

This study involved a large patient population (2,017 patients) whose data were

uniformly collected prospectively and categorized by a single neurosurgeon. This perhaps mitigates some of the usual criticisms of observational bias. Hopefully, our findings will therefore contribute to identification of some pitfalls in the process of medical referral.

Weaknesses of the study

The limitations of a cross-sectional as opposed to longitudinal study have been noted by Muzzin.¹ To adequately appreciate the problems of referral and offer solutions, a longitudinal study examining patients' backgrounds, and assessment of patients', primary care physicians', and specialists' evaluations of the success or otherwise of referrals would be required.

Ultimately the impact of failed or unsatisfactory referrals on health care budgets would have to be assessed and suggested improvements to the process incorporated into comprehensive health care plans.

The applicability of the results of this study to the referral process in general might be questionable due to the fact that all referrals were to one neurosurgeon. The costs to society in terms of patient morbidity and mortality and the considerable economic costs of modern neurosurgical management of patients would argue for the importance of this study.

Future direction

A more elaborate and complete study including such variables as patient age, sex, ethnicity, place of residence with respect to consultant, diagnosis, specialty of referring doctor, number of referrals involved, quality and validity of referral would be needed in order to fully understand this truly complex act. Patient satisfaction surveys as a measure of an important outcome measure would be valuable. Finally, and most importantly, the impact of level of information on the outcome of the medical (in this case neurosurgical) care for individual patients could be assessed by in-depth longitudinal studies. Although our results show that almost two thirds of patients referred to a single neurosurgeon were fully informed as to what type of specialist they

were seeing and for what reason, the need for improved communication between physicians and their patients is evident. A measure that has been advocated to achieve this end is the agreement between family practitioners and specialists referring to other specialists on guidelines for appropriate referrals.¹³

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