PRACTICE OBSERVED

General practitioner and long term care of patients with a spinal injury

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Abstract

A questionnaire was sent to disabled people to ascertain what part their general practitioners played in their long term care. The average consultation rate was 4.40 per patient a year. Overall, it appeared that the patients were most concerned with the general practitioner's attitude towards them and the general practitioner's availability.

Introduction

Throughout my attachment over several years to units that care for young disabled people and patients with spinal injury I have been struck by the small part that the general practitioner appears to play in the total care of such patients and the apparent dependence of the patient on the unit. I attempted to measure, by means of a questionnaire that was delivered to members by the Spinal Injuries Association, what part the general practitioner plays in the long term care of patients with spinal injury and perhaps also indicate the potential role of the general practitioner.

The "patients" are doubly selected, of course, being members of the Spinal Injuries Association and having replied to the questionnaire. It is likely that the 450 respondents comprised roughly 4% to 6% of the total number of people in the United Kingdom who have suffered spinal injury. Spinal injury, however, is not a notifiable disease, and an appropriate incidence may be deduced only from the numbers of patients that are known to specialist centres.

Of the 450 replies received, men outnumbered women in a ratio of 3:1 (336:114), and the age distribution was lower than that of the average population (table 1). All but 10 of the patients had an injury to the spinal cord, and those 10, who had a disability that resulted from other causes, are excluded from the results: 39% (176) had cervical cord lesions and 58.9% (264) thoracolumbar lesions. Ten of the answers on the questionnaire were incomplete.

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TABLE 1—Distribution of disabled respondents by age and sex

	<30	30-39	40-49	50-59	Over 60
Total No. %	107 (23.7)	122 (27.1)	104 (23.1)	73 (16.2)	44 (9.7)
Male	48	55	38	22	14
Female	59	67	66	51	30

Note: 71% of respondents were under 50 years of age.

With regard to distance, 71% lived more than 20 miles from their unit and 42% further than 50 miles. Those at a great distance were usually from the south or south west of England, south Wales, and northern Scotland. Since this questionnaire was completed new spinal injuries units have opened in Salisbury, Wiltshire and Brockley Hill, Stanmore, Middlesex. Table II gives the duration of the disability.

TABLE II—Level of onset and duration of disability of the respondents

	<5	5-10	10-15	15-20	20-25	Over 25
Total No. %	108	111	76	46	51	56
Male	48	55	38	22	21	21
Female	60	56	38	24	30	35

Expectations

During their initial stay in hospital patients who have suffered a spinal injury undergo intensive rehabilitation to enable them to live as independent a life as possible. In the questionnaire they were asked what action they would take or where they might seek help under conditions that have occurred or may occur while they live at home. The choices that they were given in the questionnaire were (a) the specialist unit, (b) the district nurse, (c) the general practitioner, (d) the local accident and emergency department, and (e) social services or any other agency.

In the event of a non-specific febrile illness or, more specifically, a febrile cold with a productive cough, most would seek help if they sought it at all from their general practitioner regardless of the distance they lived from their unit, though a few (11.4%) who lived within five miles of such a unit would contact the hospital directly. The difficulties faced by a paraplegic patient with regard to chest drainage did not seem to influence the choice of those particular patients.

When faced with difficulties related to urinary drainage, such as catheter bypassing and problems with urostomy, the expected action would depend very much on the distance that the patient lived from the unit. 40% of those who lived within five miles would refer themselves directly to the unit, but those who lived greater distances were more likely to contact the general practitioner (roughly half of those who lived more than 20 miles from the hospital). Roughly a fifth would first contact the district nurse regardless of distance.

Minor skin problems are important for the patient with a spinal injury. Regardless of the distance from the unit, a third of patients with such a problem would seek advice from their general practitioner and a further fifth from the district nurse. A third of those who lived within 20 miles and a tenth of those who lived further than 100 miles from the unit would refer themselves directly to hospital.

When considering possible alterations or modifications to their house three quarters would most likely seek advice from the relevant department of social services. Few (less than 5%) would consider seeking help from either the district nurse or the general practitioner. The expert advice available in their own unit from the attached occupational therapist was unlikely to be used (5%).

It might be expected that a spinal injury would have a devastating effect on relationships within a family, but especially, with the age of the long term. Should difficulties arise in the family, however, only a third would seek help from medical agencies. 24% felt it was their own problem to be sorted out within the family. 41.5% might seek help from a source including close friends, the Citizens Advice Bureau, the social worker, the church, the Spinal Injuries Association, and marriage guidance counsellors. Only one patient in six felt that the general practitioner had anything to offer in this regard.

In any of these potentially difficult situations it was rare for the patient to consider the local accident and emergency department as a source of help.

Only when faced with an acute problem with catheter drainage would a small proportion (2% of all respondents) resort to that. This is in stark contrast with the use made of this department by the general population.

Contact with the general practitioner

The questionnaire asked how often respondents had seen their general practitioners in the past 12 months. The average consultation rate was 4.40 per patient a year (women 4.10 a year, men 4.50 a year). These figures take no account of telephone consultations, requests for repeat prescriptions by letter or telephone, or attendances at visits in hospital departments. Patients who had cervical lesions consulted at a rate of 4.33 times a year and those who had thoracolumbar lesions 4.39 times a year. The consultation rate appeared to vary with the age of the patient. In those under 30 the rate was 4.67 consultations a year, falling to 3.69. Then from 40 onwards it gradually increased to 5.98 consultations a year in those over 60. I have stated that the consultation rate "appeared" to vary with the age of the patient. It may, in fact, be that this variation was related more to the duration of the disability, for in those who had been disabled for less than five years the consultation rate was five a year, thereafter it fell steadily and began to rise after 25 years of disability. It is likely that the higher consultation rate in the early days of disability is related to the period of adjustment by the patient and that the rate in the consultation rate for older patients will be more for reasons similar to those causing the rising consultation rate with age in the general population. The consultation rate with the general practitioner did not vary appreciably with the distance that the patient lived from the unit.

To identify the common reasons for a consultation with their general practitioners respondents were asked the reason for their last personal contact. Illness that was either intermittent or related directly to their disability was an important reason for 245 (54%) of the last consultations. Repeat prescriptions of drugs or appliances were a primary or contributory reason in 148 (32.8%) consultations. Certification—for example, national insurance or private insurance—was the reason for 62 (13.7%) consultations.

The question was asked: "What was the single most important contribution that your general practitioner made to your welfare?" Twenty one did not reply. Of those who did, only 16 (3.5%) considered that the main contribution of their general practitioner was medical expertise, which was usually either technical or clinical. "He changes my catheter." "He treats my illnesses efficiently."

The availability of the general practitioner was most important for 79 (17.5%). "Comes when I call." "Visits me at short notice." "He or his partner is available 24 hours a day." A similar proportion (17%) considered that making it easy and convenient to obtain a repeat prescription was an essential function of their general practitioner, though some of the statements were double ended. "He is a prescribing agent." "He prescribes whatever I ask for without bothering to see me. A very satisfactory arrangement."

A few (3.1%) were grateful for what their general practitioner did but implied some effort on their part was needed to get him to do it. "He stays away unless called in." "Does what I tell him." "Silly four (4.4%) thought that the general practitioner's main function was readiness to refer to other agencies. "Rushed me into hospital when I was ill." "Found me a place at a day centre." "Willing to refer me to the unit when they were not." "Unusually, but not surprisingly, 57 (12.6%) considered that their general practitioners contributed nothing to their welfare. "He is useless." "Impatient and unwilling." "Even when I ask, he is unwilling to visit."

Most such answers seemed to reflect some deficiency of the general practitioner's activity, skill, or availability, but many implied a negative attitude either on the part of the patient or the doctor. In contrast 123 respondents (27.3%) considered that the general practitioners' most important contribution was their relationship with them. It was difficult to define this group, but words such as "understanding" and "care" occurred or were implied often. "Understands my illness." "Treats me as a responsible person." "He is my pal." "I feel relaxed at having a general practitioner who receives the discharge note."

There seems to be no doubt that the attitude of the general practitioner to the patient and the general practitioner's availability and appreciation of his or her shortcomings far outweigh medical expertise in the eyes of the patient.

Discussion

Statistically, it is likely that one general practitioner in three is personally responsible for a patient with a spinal injury. It is unlikely then that a general practitioner will have particular expertise in the long term management of such patients. On the other hand, on leaving hospital the patient may well understand fully his or her own problems and their management. How well he or she shares this expertise with the general practitioner depends on their relationship and on the general practitioner's attitude. Not all of us adapt easily to a situation where the patient is better informed than the doctor. The doctor may, however, find some remedy in the excellent practical guides available from the Spinal Injuries Association.¹

Obviously, mutual benefit may be gained by the general practitioner and the practice nurse participating in the rehabilitation and planning of aftercare during the patient's initial stay in hospital. To achieve this, though, it is essential that the general practitioner is informed of the patient's initial admission. This rarely happens, and often the first official information that the general practitioner receives is the discharge note.

In fact it is rare for the general practitioner to visit the patient during the initial admission. Though the numbers are small, perhaps it is important that the 5% of patients who were visited by their general practitioners during the initial stay consulted them at a higher rate (7.05 consultations a year) than average. Does this reflect an unmet need or an unsought source of help?

The answers provided in the questionnaire were remarkable in several ways. Firstly, I was struck by the lack of bitterness and anger in most of them and this despite some overt depressions. Usually the response was eminently constructive but occasionally indicated hurt feelings. "Why is it that when I went down as an examination I could not get my chair in the cubicle so I had to get undressed in the public waiting room?" (a young girl with spinal bifida).

Despite the respondents being a self selected group, the answers to the questionnaire reflected a high standard of rehabilitation and constructive self help developed by the specialist units. What was most remarkable, though, was how matter of fact (many truly laconic) most of the answers were. The consultation rate with the general practitioner was only a little above the general average. The expected and actual use of the general practitioner and community services was not dissimilar to that in the general population (except for their expected use of the accident and emergency department).

Thus the analysis of the response to the questionnaire shows that people with a disability are precisely that—people with a disability. The disability may be permanent but the effects may be diminished by the greater availability and accessibility of caring expertise in all of us, expert and artisan, medical and lay.

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Practical considerations in conducting research in primary medical care

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This paper focuses on issues relevant to conducting research in primary medical care, which will be illustrated from my own experience and that of my colleagues. Over the past two years seven research assistants have been employed in our department who come from a variety of backgrounds. They include a physiotherapist, several nurses, and an arts graduate. We work on several different projects, and the one that I have been most concerned in was a comparison of the efficacy of different antibiotic treatments for acute otitis media.

After otitis media was diagnosed by the general practitioner patients were entered into a trial. Parents were asked to keep a fairly detailed diary of their children's health over the next 20 days. I visited them at home within 24 hours, checking that they understood what they were required to do, taking a brief medical history, and dealing with queries. From then on I was responsible for ensuring that patients attended for review, usually one week later, and for performing audiometry, usually at one month and six months.

Although other projects in the department are different in many respects, a common feature is that they all require a high degree of contact with patients and considerable cooperation from the patients. In the past two years roughly 1700 visits have been made to patients during six studies relating to otitis media, asthma, and prescribing in general practice. I have had 350 contacts with patients.

This paper discusses the role of the research assistant in relation to the patient and in the research team.

Aims and objectives

As in any research our aim is to obtain as much relevant information as possible, with minimum bias and maximum accuracy. Because we carry out research in general practice we need to cultivate the sort of relationship with patients that will give them a sense of the importance of the project and of the value of their contribution. We also know that the cooperation of these patients will be needed in future on other projects, and with a fairly static population and limited number of patients, public relations are obviously very important. With the range of projects being carried out at Southampton it is not hard to imagine that all the members of one family might be participating in different projects at the same time, and even the most cooperative ones might become irritated. There is no place for hit and miss research in general practice.

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Relationship with the patient

All the research assistants would agree, I think, that the contact with patients is the most rewarding part of our work, even if it may be fraught at times. All of the research assistants whom I have talked to suggested that they have had some anxiety or inhibition about the demands that they were making on the patient. One remarked that when she phoned up to ask for an appointment she felt like a double glazing salesperson—selling something she was fairly sure the patient would manage happily without. Two aspects of the study of otitis media helped to ease this dilemma. Firstly, our approach to the patients was supported by their general practitioner. Several research assistants noted the transformation that took place in patients' attitudes to them when the general practitioner was mentioned by name. This was an obvious advantage for us, for example, over the market researcher, who is restricted to "cold selling." Secondly, we became less critical of our own positions as we developed some skills, such as audiology and tympanometry, through which we were able to contribute to the care of these patients. Though it may be a small contribution, it does help to feel that we have something to offer in participating in research with the patient.

The recruitment of patients for research projects raises ethical questions, not the least of which is that they may be recruited by general practitioners during a weak moment when it is difficult for them to refuse. We are aware of the need to be sensitive to the patient's perspective and to use the initial contact appropriately for the individual. Far more important is the opportunity of meeting the patients, establishing a relationship, and persuading them about the value of the project.

As I have worked on a project for two winters, it has become second nature for me to assess the attitude of the child's parent. We meet all sorts—from the meekly subservient parent, who has agreed to take part but is clearly anxious to "get it right," to the rather aggressive one, who has somewhat reluctantly agreed to take part but thinks it's all rather a waste of time. We approach front doors with little idea of what is waiting, which requires a fair amount of adaptability and pragmatism. We need to pay attention to what the parent wants to get out of the visit. Some, though willing to cooperate conscientiously, are busy and ask that they transact the business quickly, spell out exactly what is required of them, and leave as quickly as possible. At the other extreme are mothers who are hungry for human contact and delighted to have someone to talk to. I try to space my visits so as to allow adequate time for chatting if that seems appropriate. It seems to me that if the mother wants to trade her cooperation in the project for a bit of human concern and interest it is not an unreasonable exchange. I have never refused a cup of coffee, although some days I feel as though I'm awash.

I think that it is important to give the impression that one is genuinely interested in the child and not to treat the child as someone who happens to have an interesting condition. The

conversation often ranges from schooling to leisure activities to sports, and even on. Striving to make the mother feel at ease in my visits to talk through family problems, and I am happy to be used as a sounding board, although I keep direct advice to a minimum. This has never caused problems for me, but a colleague was faced with a heavy problem when one woman whom she was interviewing was threatened with suicide. She was unsure whether to pass on the information to the relevant general practitioner or whether that was a breach of confidentiality. Though all of this may seem to be irrelevant to the project, it has proved invaluable in building up good relationships and facilitating long term cooperation.

Questions from patients

By the time I arrive at the mother's front door she has had some time to think about her child's condition and what the doctor said. She may have a whole battery of questions for me—about the research project, which I am happy to answer, and about the child's condition. This is more of a problem, and I usually explain that I have no medical background to fend off questions. If the problem is not understanding what otitis media is it helps to show a line drawing. There is a grey area of commonsense advice that I would certainly give a friend, if asked, but which I am reluctant to pass on to patients in case it is perceived as being backed by some special authority. The problem of what to and what not to disclose to patients arises again in relation to the results of audiometric testing, which we carry out on many of the children who are participating in the project. When the test is completed the first question that the parents ask is, "Well, how is he?" I have often felt pulled between not knowing how much I was supposed to disclose to the patient and the knowledge that parents might well take offence as an indication that a serious problem exists. There are real problems here for the research as well as for clinical care, and I can certainly think of situations in which passing on information to the patient might even create potential biases in the research findings.

Patients' needs v project needs

By going into patients' homes one becomes aware of just how fragile life is for some families. Often on my project it was only on the first visit that patients realised how much was being asked of them. In explaining what they were expected to do I had to find a middle way between emphasising the importance of accurate, conscientious recording and making it sound too much like hard work. I have had to pursue parents who failed to bring their child up for review—the child was better and they did not see the point. At the back of my mind was the thought that though this follow up was desirable the main purpose was to provide research data. I have felt torn between the obvious stress imposed on the family (especially if they had no car, lived some distance away, and had several small children) and the needs of the project. At times I have coaxed a parent, emphasising the importance to the child's well being, being conscious that my main motivation was collecting data. We have to be convinced of the potential value of the research we do so that we can see the data collection as a means to a desirable end.

In the early days of the project I was conscious of the need to "put the patient first" and went out of my way to arrange visits and appointments at the patient's maximum convenience, phoning up and leaving it to them to suggest a time. Before long I sensed that this made patients uneasy, and in fact my well meaning attempts to accommodate them indicated that the purpose of the visit was not really important and that they were doing me a favour in seeing me. I was creating a dichotomy between research and clinical care which did not really exist for them. This was obvious when it came to arranging appointments for audiometry. I had assumed that patients were more likely to attend appointments that were arranged entirely at their convenience but was disappointed to find that in fact attendance was extremely poor, and for many I had to go to see them more than three appointments. I changed tack slightly and made an initial offer of an appointment by phone, which in most cases was acceptable, but an alternative would be offered if it was in-

convenient. The attendance improved. A further improvement occurred when instead of phoning I sent out appointment letters by post.

Research assistant in the research team

There are other aspects of the research assistant's role. Perhaps most central is what the role is intended to achieve. This seems to vary from one department to another and one project leader to another. My own contacts say simply that I am required to carry out duties as determined by the head of department, and that clearly allows for a considerable difference in emphasis.

One problem identified by research assistants at the health centre was being drafted in for the data collection without having participated in the thinking or planning of the research. One likened it to "giving birth and becoming responsible for a child without having been pregnant." It seems to me to be like surrogate mothering, where one does not conceive the baby but goes through the inconvenience of pregnancy and anguish of labour only to hand the baby back to its natural parent. On the other hand, one does not want to bother the project leaders with trivia, the reason for one's employment being to relieve them of such trivia. If one has not been involved in the thinking and planning stages, however, it is not always clear what the implications of apparent trivia might be in the scope of the research. I am aware of the pressures on the time of project leaders, but I think that time spent orientating research staff, enabling them to get "under the skin" of a research project, and exploring the issues that underlie it will reap benefits in the long term.

The issue here is the project leader's conception of the role of research assistants. Some see it as essentially that of dogbody, undertaking jobs as and when delegated, and undoubtedly this is a tenable position. On the other hand, it is possible to see the role as part of the research team sharing insights and ideas and making a contribution to the project that goes beyond clerical and manual work. The latter position is likely to be more fruitful, especially since most project leaders, who are also general practitioners, have heavy demands on their time as well as the conflict between clinical responsibilities and research interests. Such involvement would not only reduce the burden on project leaders but also improve the quality of the work of research assistants on routine tasks. All of the research assistants who I spoke to cited tiredness as the major tribulation of their job. Most research projects seem to generate a huge amount of clerical work. In our case the worst job was undoubtedly coding 960 000 items on computer sheets. I think, however, that all were agreed that tedious is acceptable when the task is one aspect of a wider project in which one has fully participated and that there is a vested interest. A sense of commitment must surely enhance the accuracy with which clerical tasks are carried out.

Research assistants should also expect some training and development in their jobs. This will take many different forms, depending on the interests and capabilities of the research assistant and the needs of the project. One problem with short term research contracts, which are undoubtedly necessary in the current economic climate, is that they discourage commitment to the training of research staff who are here today and gone tomorrow. None the less, I think that all employers have a responsibility to offer training to their staff, and since the high street chain stores take this seriously surely university departments should as well. Such training would enable research assistants to develop skills that are relevant to the project or provide skills for research in the wider sense.

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