Disablement and care: a comparison of patient views and general practitioner knowledge

D. L. PATRICK, PH.D, MSPH, H. PEACH, B.SC, MB, I. GREGG, MRCP, FRCGP

SUMMARY. A questionnaire was used to assess general practitioners' knowledge of handicaps and service use among disabled patients in a group practice. The disabled patients were identified by a postal screening questionnaire. Sixty-eight were subsequently interviewed to assess the severity of restrictions on their activities and to collect information about informal support and use of community or hospital services. The areas of life in which the disabled were most affected by their medical conditions were sleep and rest, household management, emotion and mood. Relatives assisted the disabled considerably with all daily activities but more help was requested. Most disabled patients had consulted their general practitioner or attended casualty and out-patient clinics, but only a minority had used other community services. Prescription of drugs was considered the most important service the doctor provided. A second questionnaire, which the general practitioners completed with the help of their records, revealed that they knew of only 50 per cent of the difficulties with daily living reported by the disabled and even less of the aids, appliances and services used. A better awareness of these facilities among general practitioners might lead to a more effective distribution of resources among their patients.

Introduction

SURVEYS of caring services for physically disabled people have concentrated primarily on severely disabled persons known to local authorities under the Chronic Sick and Disabled Persons Act, 1970. There have been fewer studies of the care of non-registered disabled persons living in the community. It is well known that general practitioners have more contact with the physically disabled than any other professional or agency. Harris and colleagues (1971) found that 90 per cent of the registered disabled had consulted their doctor at least once over a 12-month period. Moreover, the Consumers' Association (1978) found that the general practitioner was the only person with whom one in 10 disabled had any contact at all. As general practitioners see more of disabled people than any other professionals, they are in the best position to refer patients to other caring agencies such as the social services (Seebohm Report, 1968).

Referral of a disabled person to the social services or other agency is a complex process involving at least three steps: professional assessment, decision on whether to turn away or treat, and decision on whether to treat at the initial doctor-patient contact or to move the patient further into the provision system. To make these decisions, general practitioners must be aware of their patients' difficulties with activities of daily living as well as the aids and services already used. Doctors should also be aware of the range of services available. No study has assessed general practitioners' knowledge of these services, nor their knowledge of their patients' disabilities and care.

D. L. Patrick, Senior Lecturer in Social Science, St Thomas's Hospital Medical School, London; H. Peach, Lecturer in Community Medicine, St Thomas's Hospital Medical School, London; I. Gregg, General Practitioner, Kingston-upon-Thames.

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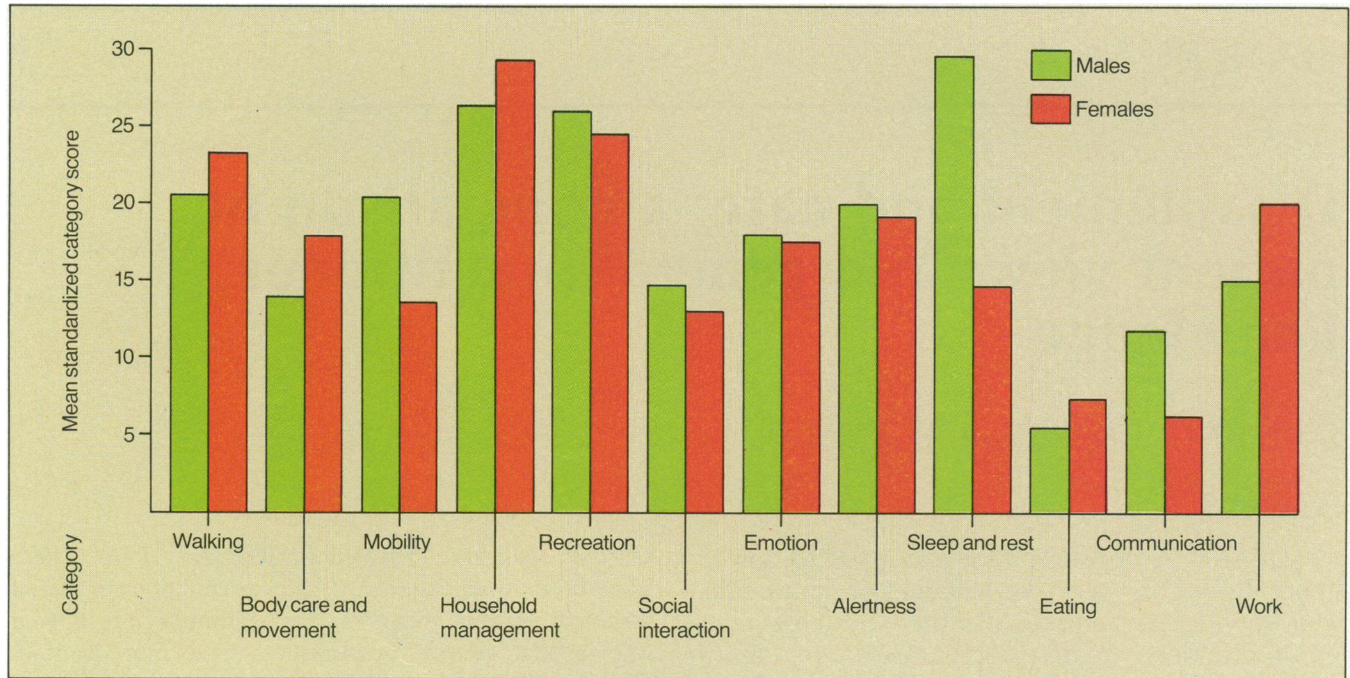
Aim

This study was designed to assess general practitioners' working knowledge of their disabled patients, including the less severely disabled and those not registered by the local authority.

Methods

The study was conducted at a general practice in Kingston-upon-Thames. The practice list numbered 6,012 and there were six doctors, all of whom were part-



FLP category scores of disabled patients by sex (standardized so that maximum possible score = 100).

time: three male and two female principals and one male trainee. In addition to the general practitioners, the primary health care team consisted of two health visitors, two district nurses, two practice nurses, two secretaries and two clerical staff. It was practice policy for the health visitors to make routine visits to all patients over 75 years old at least once a year. In addition, all chronically sick patients were visited at home if the general practitioner judged it necessary.

A one-in-18 sample of the practice records was chosen, and addresses were checked to ensure that no two members of the same household were included in the sample. When records of children under 16 years of age were sampled, the preceding adult record was used, but counting recommenced from the child's record. In this way, 300 households were selected as the study population.

The study was subsequently conducted in three phases:

1. Screening phase. The reliability of using a self-administered postal questionnaire to identify disabled people in a general practice or community has been described elsewhere (Peach *et al.,* 1980: Locker *et al.,* 1981; Patrick *et al.,* 1981). A questionnaire was designed to identify adults who had difficulty with walking, self-care, employment, household chores or visiting family and friends. Respondents were also asked about the medical problems which caused such difficulties. Respondents were regarded as disabled if they gave a positive response to one or more of the questions. The questionnaire, letter and reply-paid envelope were sent in a first mailing to the 300 sample households. Two reminder letters followed, with an additional copy of the questionnaire enclosed in a third mailing.

2. Interview phase. Field workers interviewed a sample of disabled respondents between three and six months after the postal questionnaires were returned. The severity of disability was measured by a questionnaire known as the Functional Limitations Profile (FLP) (Bergner *et al.,* 1976; Patrick, 1981). This comprises 136 statements covering 12 areas of daily living with which the respondents must agree or disagree. Points are scored according to the severity of the disability, and an individual's disabilities can be summarized as a single overall score or 12 separate category scores. Structured questionnaires have been shown to collect valid data about medical conditions (Warren, 1976) and about use of formal and informal services, even among the elderly (Green *et al.,* 1979). Therefore, information was also collected from respondents about the use of inpatient, outpatient and casualty facilities, use of formal services (occupational therapist, physiotherapist, district nurse, health visitor, social worker, bathing attendant, meals-on-wheels, home help) and institutions (luncheon clubs, day-care centres, physically handicapped centres and day hospitals), and amount of informal support received from relatives.

3. Assessment of general practitioners' knowledge. A record abstract excludes unrecorded knowledge built up over time and underestimates a doctor's working knowledge of his or her patients. A self-administered questionnaire completed by the doctor on each patient with the help of his or her records (Peach *et al.,* 1979) gives a more accurate picture. Between eight

Table 1. Use of community services as reported by disabled respondents (n=68).

Service	Within past 14 days	Last used within past one to nine months	Over nine months	Beyond recall	Never
GP	17	41	10	0	0
Optician	1	23	25	11	8
Dentist	4	15	2	22	25
Chiropodist	5	12	1	5	45
Health visitor	2	10	3	3	50
Physiotherapist	2	6	8	12	40
Social worker	2	6	3	1	56
District nurse	2	3	2	7	54
Home help	3	1	1	3	60
Occupational therapist	2	1	4	1	60
X-ray unit	0	2	5	16	45
Casualty or outpatient	0	26	39	3	0
Luncheon club, day-care centre, physically handicapped centre, day hospital or day centre	5	2	9	0	52

and 12 months after the patient interviews, the doctors were asked to complete a structured questionnaire about the health and care of each of their disabled patients. The questionnaire was similar to that used for the patients except that it referred to a 12-month period on either side of the patient interviews. Information from the general practitioner questionnaire was compared with that obtained from the patients at interview.

Results

At 26 of the 300 sample households, the addressee had died or had moved away from the practice. After three mailings, an 87 per cent response was achieved from individuals in the remaining households. All non-respondent households (35) were followed up by a field worker, and an additional 11 completed questionnaires were obtained. This gave a final response of 91 per cent, representing 793 individuals living in 250 households. Eleven per cent of these people (89 individuals) were classified as disabled using our definition. Of these, 51 (57 per cent) were women and 38 (43 per cent) were men. The mean age was 56 years. A greater proportion of the sample households were in social classes I and II (35.5 per cent) compared to the 1971 census figures for Greater London (23.1 per cent).

Field workers interviewed 68 of the disabled. Twenty-one had died, moved into an institution or out of the area, or refused. The mean age of those interviewed was 68 years; 29 were men and 39 were women.

Disabled respondents reported an average of two medical conditions each. The most commonly mentioned was arthritis, which accounted for 13 per cent of the total conditions reported. Each respondent had an average of 10 symptoms, the most common of which were visual difficulties and pain or stiffness in limbs and joints. The Figure shows the FLP for the 68 disabled interviewees by sex. The overall pattern of dysfunction was similar for men and women except that ill health had a greater effect on sleep and rest, communication and mobility among men. Medical conditions appeared to have a significant effect on all areas of life except communication among women and eating among both sexes. This effect was most marked on sleep and rest among men and household management among both sexes.

Table 1 shows the community services which disabled patients reported using. The community service most frequently used was the general practitioner. Fifty-eight (85 per cent) respondents reported seeing their doctor within the past nine months; 17 (25 per cent) reported a visit within the fortnight preceding the interview. Fifteen of those who had visited the surgery within the last 14 days went there to collect a prescription without actually talking to the doctor. Prescribing drugs was considered the most important service the doctor provided.

Relatives helped the disabled respondents most with housework and preparing, cooking or eating meals (see Table 2). The spouse gave the most help to their disabled partners for all activities studied. The only formal support disabled patients received was from home helps, and the amount of help was minor compared with that from relatives.

Twenty-five disabled respondents reported that they needed more help to make their daily lives easier—most commonly help with housework or shopping. Many respondents noted that it was difficult to get help with housework, even if one could afford it. Other assistance requested included home hairdressing, pensions counselling and "a visiting friend". Twelve disabled patients requested more help at night. Three needed help going to the toilet, one needed help using the bed pan and two needed help with injections or applying dressings. Six respondents needed help every night, while two needed help on a number of nights every week.

Table 2. Informal and formal support received by disabled respondents (n=68).

Activity	Number of respondents receiving help	Amount of help in two weeks preceding the interview*				
		Total	Spouse	Other relative	Other	Home help
Walking/going upstairs	12	118	63	30	25	0
Travelling by bus/tube	1	2	2			
Night-time activities	8	47	30	3	14	0
Housework	68	1011	709	210	78	14
Getting out of bed/chair	12	127	71	39	17	0
Using toilet	5	62	20	28	14	0
Bathing/dressing/foot care	27	99	68	8	23	0
Preparing/cooking/eating meal	59	754	532	150	72	0

*Number of persons times number of days per person per week.

Table 3. Difficulty with activities of daily living (n=51).

Activities of daily living	Number of people having difficulty	
	Patient interview	GP questionnaire
Walking	6	4
Getting outside house	7	3
Crossing road	9	4
Travelling on bus/train	7	6
Climbing stairs	6	3
Getting in/out of bed	7	5
Dressing	5	3
Kneeling/bending	23	7
Bathing/washing	11	4
Getting to/using toilet	4	2
Working	13	5
Doing job of choice	10	5
Doing housework	16	5
Visiting family/friends	10	6
Total	134	62

The general practitioner questionnaire

A general practitioner questionnaire was completed for 51 of the interviewed disabled, a further 17 having left the area or changed doctors by this stage of the study. In Tables 3 to 5 the information obtained from the patients at interview is compared with the information from the general practitioner questionnaires.

Of the 134 difficulties with activities of daily living reported by the disabled, the doctors knew of 62 such complaints being made over the 12-month period on either side of the interview (Table 3). The activities they were least aware of were kneeling/bending, bathing/washing and doing housework. Kneeling/bending and doing housework were the commonest activities of daily life with which the disabled had difficulty. The doctors knew of nine instances where the disabled said they were using formal services (Table 4). As shown in Table 5 they had knowledge of 14 of the 77 instances where surgical appliances and aids were being used.

Discussion

The general practitioners knew about less than half the activities of daily living with which their disabled patients reported difficulty and were almost totally unaware of what services or aids and appliances they were using. For one of the disability items, namely visual difficulties, where the disabled themselves could consult an optician, there was no apparent evidence of unmet need. All such respondents had seen an optician within the previous one to nine months and nearly all had spectacles at interview. But there was circumstantial evidence of need among disabled people who had an activity restriction for which referral from a general practitioner was necessary in order for the patient to see another professional or to obtain an appliance or aid. For example, the FLP indicated that the greatest difficulties were in household management. Yet the general practitioners were aware of housework difficulties among only 30 per cent of those who had them. None of

Table 4. Formal services (n=51).

Service	Number of people using service	
	Patient interview	GP questionnaire
District nurse	1	1
Health visitor	6	1
Social worker	6	1
Chiropodist	7	0
Home help	3	0
Meals on wheels	1	0
Dentist	14	1
Optician	12	2
Physiotherapist	4	0
Occupational therapist	6	0
X-ray department	2	1
Casualty/outpatients	13	2
Day-care centre	1	0
Physically handicapped centre	1	0
Total	77	9

Table 5. Appliances and aids used.

Appliance/aid	Number of people using appliance/aid	
	Patient interview	GP questionnaire
Elastic stockings	4	0
Incontinence pads	1	0
Artificial limbs	1	0
Surgical footwear	2	1
Surgical corset	5	0
Hearing aid	8	0
Glasses	41	9
Walking aid	15	3
Total	77	13

the respondents had aids which could assist with housework and only a few had seen a social worker or occupational therapist who could have diagnosed the need for such aids. Only three respondents had a home help, but housework was the activity with which respondents were receiving the most help from their relatives.

The FLP also indicated dysfunction in self-care and mobility, and respondents were receiving a lot of help from relatives in: preparing, cooking and eating meals; getting out of bed or a chair; walking and going upstairs; and bathing, dressing and foot care. Nearly all the respondents who had mobility difficulties had either a walking aid, surgical footwear, elastic stockings or artificial limbs, but the general practitioners seemed unaware that their patients had these aids and appliances. None of the respondents had aids to assist self-care, but most of those with self-care difficulties had seen a chiropodist within the past nine months.

Relatives might well have been helped by being told more about other caring agencies for disabled patients. Providing additional services may prevent a breakdown in informal support, which can lead to institutionalization. For example, Sanford (1975) found that 12 per cent of all geriatric admissions were for patients whose relatives or friends could no longer cope with them at home. Over the 12 months between initial screening and the doctors completing their questionnaires, 38 patients dropped out of the study, some of whom had gone into institutions. Given the demand for help at night revealed in our survey, night services in particular may prevent institutionalization.

Not only did the general practitioners not know about day-to-day difficulties, but they did not seem to be aware of the community services and aids or appliances which their patients had. Community services are relatively scarce resources and it is important that they be directed to those most in need. In order to do this, general practitioners must not only know which of their patients are in need of community services and what aids or appliances they are already using, but they must also be aware of changing needs among those receiving services. The disability status of patients changes over time, so that they can come to need more or less of a particular resource, different resources or none at all.

It has been suggested that general practitioners do not see themselves as responsible for the social needs of their patients (*British Medical Journal,* 1979). A recent report on the prevention of psychiatric disorders in general practice (Royal College of General Practitioners, 1981) emphasizes the idea of the doctor as an agent of change with special opportunities for helping people to cope with the changes in their lives produced by illness, accident and bereavement. In our study the disabled themselves gave prescribing as their doctor's most important role. The low use of community services and institutions (except casualty or outpatient clinics) could be taken as circumstantial evidence that the general practitioners also saw their main role as prescribing drugs.

Local authority social service, education and housing departments and central government departments clearly have an important part to play in caring for elderly and disabled patients in the inner cities. But the services provided by these departments place greater demands and stresses on the health services and create a need for greater co-ordination. The London Health Planning Consortium (1981) has recommended the establishment of management units for co-ordinating community services and the appointment of a senior officer to plan community services on a local basis. Our findings support the need for such co-ordination and centralization of responsibility. But whether disabled persons get all the services that can help them ultimately depends upon their general practitioners being aware of their disabilities and the services and aids or appliances they are using or need to use.

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Address for reprints

Dr H. Peach, Department of Community Medicine, St Thomas's Hospital Medical School, London, SE1 7EH.

Deserting the pub?

Representatives of the licensed trade have for some time been of the opinion that drinkers in Britain are deserting the public house. A recent survey by the National Opinion Poll organization confirms this trend. In 1979, 47 per cent of the population claimed to have visited a pub during the previous month. The figure during 1980 was 43 per cent. Twenty-nine per cent of those still going to pubs said they spent less time in them; 47 per cent said they could no longer afford to drink as much.

Source: *Alliance News,* Sept/Oct 1981, 7.

Headaches

A recent national survey on headaches and their causes has been published by Gallup on behalf of Optrex. Seventy-four per cent of women suffer from headaches at some time, compared with only 55 per cent of men. When asked about the causes of headaches, stress and tension were given by both sexes as the most frequent cause, followed by eye-strain and noise. Another major cause quoted by 15 per cent of men but by almost no women was hangovers, particularly by men in the 16–24 years age bracket. The highest incidence (83 per cent) is among those working part-time, the majority of whom are women. Only 53 per cent of men and women over 65 get headaches, compared with 73 per cent of men and women in the 35–44 age group.

Source: Optrex press information.