Identifying handicapped people in general practice

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SUMMARY. This study used the age–sex register of a group medical practice as the population base for a postal and follow-up interview enquiry to locate handicapped people and examined the possibility of the combined use of a practice diagnostic index and the patients' medical records for the same purpose. The age–sex register was found to contain deficiencies and inaccuracies despite the substantial efforts of members of the practice team to maintain it, for example, 13·5 per cent of the forms were returned as the addressee was unknown at the address.

The 81·5 per cent of householders who responded identified 353 impaired people who were subsequently interviewed about the nature of their impairment, the underlying condition, and the range of their activities. Depending upon the answers to these questions, a proportion of these people were classified as handicapped and were asked further questions. The number of impaired people and their distribution in sex and age-groups were broadly similar to the findings from other surveys. The diagnoses of the underlying conditions given by the impaired people were discussed with the general practitioners and confirmed or otherwise by the use of the patients' notes or the recollections of the general practitioners.

It was concluded that while the use of a diagnostic index would be helpful for some conditions, there would remain a substantial number of people with a disease that is potentially disabling who would have to be approached for further screening and also a substantial number of people who are handicapped, but who would be missed.

Introduction

The Chronically Sick and Disabled Persons Act, 1970, placed a statutory obligation on local authorities to collect information about the systemic needs and numbers of handicapped persons eligible for and desiring assistance from their social services departments. To what extent can notes, records and registers available in general practice be used for this purpose and for the continuing care of handicapped people not only by the practice team but also by other agencies? This article reports the use of a practice age–sex register for identifying people and locating handicapped people and discusses the limitations of using a diagnostic index for these purposes.

The direct approach of attempting to extract from the records kept by the general practitioners a list of those people who appear from the details recorded to be impaired or handicapped and adding those who might be named by the general practitioners was not attempted. Earlier exploratory studies (Jefferys, Hyman, and Warren, 1966, unpublished report) had suggested that the records kept by general practitioners were unlikely to contain adequate notes about the impairments and handicaps of patients, as distinct from details of diagnosis and treatment. A preliminary examination of the clinical notes in the practice confirmed this impression.

Methods

The practice

The study was carried out in conjunction with a group practice in Paddock Wood. The practice consisted of three partners, with attached health visitors and home nurses, practice nurses, receptionists, and secretaries. It is housed in a spacious health centre in the centre of Paddock Wood, and served a population of about 9,300 people. During the period of the study one partner fell seriously ill and a fourth partner joined. The partners usually have a trainee general practitioner and periodically have medical and other students attached to them. At the time of the study the practice maintained an age–sex register and the doctors were recording basic workload data in conjunction with research about the move of the practice into the health centre.

Identification of impaired people

The method adopted to identify the handicapped and potentially handicapped (impaired) people was to carry out a three-stage operation essentially along the lines of the recommendations of Harris and Head (1971).

In the first stage each householder was approached and asked to complete a one-page form containing 14 questions designed to identify (by name) any person in the household with substantial impairment of vision, hearing, locomotion, or ability to look after himself or who has lost the whole or part of the use of an arm, leg, hand or foot through accident or amputation or has a serious congenital abnormality.

In the second stage, each impaired person, identified on the form returned by the householder was interviewed by a trained interviewer and asked questions about the nature of the impairment and the limitations to activities which it caused.

Depending upon the answers to these questions, the interviewer decided whether to continue into the third stage and ask questions about the problems experienced and the services received by the handicapped person or to complete the interview at the end of stage 2. All people who had a stage 2 interview are referred to as impaired people and the sub-group that had a stage 3 interview as handicapped people.

The decision to approach households and not individuals was taken for two reasons. First, it was thought that there would be confusion in families if each member was asked to return a form, and there are problems in addressing a letter and form to small children. Secondly, I wanted to use a method essentially similar to the methods adopted by many social services departments so that the results and experience could be readily comparable.

It was therefore necessary to sort the age–sex register of the practice into households. This was a formidable task. All patients recorded in the active files of the age–sex register were listed in alphabetical order (instead of by year of birth). A new filing card was completed for each surname at the same address, and cross references made for persons with different surnames at the same address. After the completion of this operation, no new patients in the practice were accepted into the study population. Where there was more than one card for an address the help of the doctors and the health-centre staff was sought to find out if one of the families had moved, whether there were two households at the same address or the household contained people with two surnames or more. The names were also checked against the lists in the electoral registers. Where no further information was available, forms were addressed to bearers of both surnames.

On completion of the household lists, the postal and interview procedures already described were followed, after a check that each person identified was registered with the practice. The interviews were conducted by 11 interviewers during the period May–September 1973. As this study was carried out with the co-operation of the primary

medical care team at the health centre and the county's social services department, it was possible to ensure that all handicapped people identified in the survey and apparently in need of any available service could be referred to the appropriate person for help.

Interviews with the doctors

When all the interviews had been done the research assistant interviewed each of the partners to discuss the diagnoses or nature of the condition stated by the impaired person to be the cause of his impairment. The doctor had the patient's notes available and was encouraged to supplement these, when necessary, by his own recollections of the patient's medical history. The findings of this part of the study have been reported elsewhere (Warren, 1976a).

Results

Accuracy of the age–sex register

The more appropriate register for the purpose of approaching householders would be a family or household register, but this was not available. Even so, problems could arise, and did, where members of one household are registered with different practices, as some members of the household would not be known to the study practice, but might be included in the considerations of the householder completing the form. In the event five patients were reported who were not registered with the practice.

The study revealed discrepancies between the age–sex register and the practice list held by the executive council and revealed deficiences and inaccuracies in the data in the age–sex register, similar to those reported by other authors (Eimerl, 1960; Goodman, 1975). Table 1 shows the numbers of men and women in eight age-groups as found in the age–sex register at the start of the study and in the age–sex register after a research assistant had checked the entries and removed duplicates and persons wrongly filed in the " active " register (i.e. the register of the names of all persons currently registered with the practice). In all 511 names (301 males and 210 females) were removed in this way. This checking of the entries brought the numbers recorded in the age–sex register (4,645 males and 4,728 females) close to the total figures supplied by the executive council (4,594 males and 4,701 females) also shown in table 1.

TABLE 1
PRACTICE AGE–SEX REGISTER COMPARED WITH EXECUTIVE COUNCIL LIST

Age groups in years	*Practice age–sex register*		*Executive council list*	*Practice age–sex register*		*Executive council list*
	Before checking	*After checking*		*Before checking*	*After checking*	
	Men			*Women*		
0– 4	560	504	547	518	497	526
5–14	949	886	878	865	821	855
15–29	948	902	916	1081	1029	1008
30–49	1344	1266	1275	1269	1221	1250
50–64	556	541	630	570	559	614
65–74	200	194	224	275	268	288
75–84	101	96	104	127	124	126
85+	20	17	19	42	39	32
Not known	268	239	1	191	170	2
All ages	4946	4645	4594	4938	4728	4701

A major deficiency in the age–sex register was the lack of information about the dates of birth of 459 people which even after checking could only be reduced to 409, that is 4·4 per cent of the revised age–sex register. Comparing the revised age–sex register

figures with the figures from the executive council, it appears that the majority of these deficiencies related to persons aged between 50 and 74 years (table 1). It seems also that the revised practice age–sex register did not contain all of the infants registered in the practice, and indeed it is in this age-group and their parents that the majority of inaccuracies were found, as a result of the postal survey.

Postal enquiry

The postal enquiry was addressed to 3,287 householders by name, and replies were received from 2,680 (81·5 per cent). The Post Office returned 402 forms (12·2 per cent), and another 42 (1·3 per cent) were returned by others stating that the addressee had moved away or died. No reply was received from 163 householders (five per cent). Only six people (among those who replied) actively refused to co-operate, so the response rate was high, and among those receiving a form comparable to that obtained in other household surveys of impaired people. However, the finding that as many as 13·5 per cent of the householders identified from the revised practice age–sex register were not known or had left the addresses recorded again emphasises the need for some formal system of enquiry within general practice to bring information on the patients' records and on practice registers up to date (Farmer, Knox, Cross and Crombie, 1974).

Numbers of impaired people

Table 2 shows the number of impaired people who were interviewed and the prevalence rates per 1,000 people in each age group based on the probable minimum population (that is the estimated population in the households that replied) and a maximum population (the current practice population as recorded by the executive council). It is probable that the majority of the people whose ages were unknown were aged between 50 and 74 (table 1) so that the estimated prevalence rates in column 4 of table 2 for these age groups are too high.

TABLE 2

NUMBERS OF IMPAIRED PEOPLE REGISTERED WITH THE PRACTICE IDENTIFIED BY HOUSEHOLD SURVEY AND ESTIMATED AGE SPECIFIC RATES COMPARED WITH RATES FOUND IN CANTERBURY SURVEY

Age group	*Number of impaired persons*	*Estimated population in households that replied*	*Rates per 1000 population*		
			Based on estimated respondent population	*Based on practice population supplied by the executive council*	*Rates found in Canterbury survey* (Warren, 1974)
0– 4	8	887	9	7	7
5–14	21	1515	14	12	14
15–29	16	1665	10	8	8
30–49	45	2160	21	18	21
50–64	75	973	77	60	58
65–74	84	421	199	164	145
75+	104	250	416	370	309
Not known	—	335	—		
All ages	353	8206	43	38	50

Column 6 of table 2 shows the prevalence rates found in the Canterbury household survey (Warren, 1974) and except in the older age groups the figures are similar. These similarities occurred also with the prevalence and registration rates for the number of registered blind people (1·5 per 1,000 of the respondent population in Paddock Wood

compared to 1·7 in Canterbury), for the registered deaf (0·4 compared to 0·5) but not for " difficulty in self-care " (23·9 compared to 31). The lower figure for difficulty in self-care in Paddock Wood may be due to the smaller proportion of elderly in the population (8·5 per cent) compared to Canterbury (14·9 per cent), among whom the proportion of impaired people rises rapidly. The needs and problems of the 353 impaired people have been described elsewhere (Warren, 1976b); broadly speaking they are of the same nature and occur in the same proportions among the impaired people as has been found in other surveys (Harris *et al.*, 1971; Warren, 1974).

The conclusion about the use of the age–sex register for a *community* study is that it complicates rather than simplifies the initial approach to householders and does not add to the precision of data about the responding population compared to experience elsewhere with the use of the electoral register. However, in most general practices, it is the only feasible register available for a *practice* study. The use of a general-practice household or family register might have removed the need for much of the initial work, but the problems of accuracy and completeness of information would probably have still remained.

Discussion

Possible use of the diagnostic index

The diagnostic index was developed by the Research Unit of the Royal College of General Practitioners (Research Unit, 1971) from the earlier work of Eimerl (Eimerl, 1960; Eimerl and Laidlaw, 1969). The index records under each diagnostic term, syndrome or symptom-complex the names and often the N.H.S. numbers of patients who have been so diagnosed. The diagnoses are classified in accordance with the classification based on the *International Classification of Disease* and agreed between the Royal College of General Practitioners and the Office of Population Censuses and Surveys. The diagnostic index would be an efficient way of identifying potentially impaired and handicapped people provided that there was a close correlation between the diagnostic labels and the presence of significant impairment or handicap and provided that all impaired and handicapped people were in regular contact with the general practitioner or at least were likely to make contact at a time when in need of one or other of a variety of services. The Paddock Wood practice did not maintain a diagnostic index, but data from the present survey were used to look theoretically at the use of such an index.

Each impaired person was asked by the interviewer what was the nature of the condition underlying the impairment, and the answer was later checked in a discussion with the general practitioner. One hundred and fifty four impaired people (44 per cent) were able to state a detailed diagnosis which the general practitioner was able to confirm either from the person's records or from his own recollection; and the general practitioner was able to add a diagnosis to a further 37 of the impaired people, so that in all 191 impaired people (54 per cent) were allotted a detailed diagnosis.

One hundred and three of the remaining 162 people gave a broad label to the underlying condition (e.g. rheumatism, arthritis, deaf, or poor vision) with which the general practitioner agreed but was unable to elucidate further from the notes or his recollection (Warren, 1976a). Sixty of the 191 impaired people who were allotted a precise diagnosis gave either details of injuries (34 people) or diagnoses that are included in " other " categories in the R.C.G.P.–O.P.C.S. classification of morbidity (e.g. detached retina, ankylosing spondylosis), so that only 131 specific diagnoses are listed in table 3. The table gives the number of people whose names would have been added to a diagnostic index during a year in the practice if the consultation rates for the practice in Paddock Wood had been exactly the same as those for the rates reported in the 53 practices studied by the Office of Population Censuses and Surveys (1974). In addition, the table includes four large categories of disorders (neoplasms, refractive errors and other diseases of the eye, other deafness, and accidents and injuries).

A diagnostic index would contain a larger number of people than are shown in columns 4 and 8 of the table, if the diagnostic index had been maintained for longer than one year. An impaired person's name would only be listed in the diagnostic index against the diagnosis to which the person attributes the impairment if that person had consulted the doctor about that condition during the period of the establishment and maintenance of the diagnostic index. These qualifications must be kept in mind in discussing table 3, as well as the underlying assumption that the index will be accurate and regularly updated. Furthermore, corrections have not been made for the age and sex structure of the practice population as the table can only give an approximate indication of the composition of a diagnostic index.

In table 3, for some diagnoses, the number of impaired people identified in the survey equalled about a fifth or more of the number of patients estimated to have consulted with the declared diagnosis during the year. This applies to diabetes, multiple sclerosis, epilepsy, glaucoma, cataract, otosclerosis, bronchiectasis, nephritis, rheumatoid arthritis, spina bifida, congenital heart anomaly and other congenital anomalies, and mental retardation. However, these total only a possible 66 of the 353 impaired people identified in the household survey. The duration of some of the impairing conditions is such that many of the impaired people may not have consulted the general practitioner during the year about the underlying condition and so would not be recorded under that diagnosis in a diagnostic index. This would apply to poliomyelitis, mental retardation, deafness, blindness, injuries, and congenital anomalies. For some conditions the number who were identified as impaired was only a small fraction (one tenth or less) of the number estimated to have consulted. It could be that only a small proportion of such people consulting are impaired (e.g. herpes zoster, migraine, chronic otitis media, hypertension, varicose veins and injuries) within the definitions of the survey, and that the household survey missed a substantial number of people impaired by some of the conditions (e.g. anxiety neurosis, ischaemic heart disease, congestive failure, chronic bronchitis, asthma, and neoplasm).

It is not possible to give accurate estimates of the yield of impaired people that might be derived from a survey based only on a diagnostic index of patients attended in a general practice from the data presented in table 3 because of the assumptions underlying the data and the qualifications already made. A rough estimate would be that to have made contact with the 1,660 persons listed under the 35 diagnostic labels would have yielded between 100 and 131 (28 to 37 per cent) of the names of the people identified in the household survey and between 50 and 100 further names might have been added if the 1,023 people listed in the four large groups of disorders had also been approached. Perhaps, therefore, between 150 (42 per cent) and 231 (65 per cent) of the 353 people found in the household survey might have been identified in a survey based on patients with selected diagnoses recorded in a diagnostic index. A substantial number of other people, many suffering from neurosis, ischaemic heart disease, congestive cardiac failure or chronic bronchitis might have been identified in addition to those found in the household survey. Up to 35 per cent of those found by the survey might not have been identified, because many impaired patients probably do not consult during a year about the condition underlying their impairments.

An approach through a diagnostic index would involve either a detailed questionnaire to be completed by, or an interview with, over 2,500 persons compared to the postal approach to 3,287 householders followed by an interview with 353 persons. The estimated yield from an approach through a diagnostic index of between 42 and 65 per cent of the persons found in the household survey compares with a correspondence of 36 per cent of the names of persons identified in the Canterbury household survey by means of a search through the records and registers of a number of agencies (Warren, 1975). Many of the persons identified in a survey of agencies' records and registers would be the

TABLE 3

NUMBER OF PEOPLE IDENTIFIED AS IMPAIRED BY DIAGNOSTIC CLASSIFICATION (MORBIDITY CLASSIFICATION OF R.C.G.P.) WITH THE ESTIMATED NUMBER OF PEOPLE CONSULTING IN ONE YEAR WITH DIAGNOSIS (BASED ON PATIENTS' CONSULTING RATES, NATIONAL MORBIDITY STUDY 1970–71)

I.C.D. number	*Diagnosis*	*Number of impaired persons*	*Estimated number consulting in practice*	*I.C.D. number*	*Diagnosis*	*Number of impaired persons*	*Estimated Number consulting in practice*
040–043	Poliomyelitis	2	0	430–438	Cerebrovascular disease	6	49
053	Herpes zoster	1	37	454	Varicose veins	1	83
250	Diabetes	9	42	491	Chronic bronchitis	7	107
274	Gout	1	15	493	Asthma	3	95
281	Pernicious anaemia	2	13	518	Bronchiectasis	1	5
300	Anxiety neurosis	2	316	580–4	Nephritis	3	3
300.1	Hysterical neurosis	1	16	712	Rheumatoid arthritis	9	46
303–304	Alcoholism	1	7	713.1	Spondylosis/O.A.	1	66
310–315	Mental retardation	7	4	713	Osteoarthrosis	10	167
340	Multiple sclerosis	3	6	725	Displaced intervertebral disc	4	54
342	Paralysis agitans	1	9	741	Spina bifida	1	1
345	Epilepsy	5	27	746	Congenital heart anomaly	1	4
346	Migraine	1	68	749	Cleft palate	2	1
373	Strabismus	1	11	754	Cong. anomaly of bone or joint	4	7
374	Cataract	16	16				
375	Glaucoma	3	8	Total	All of the above	131	1660
381.1	Chronic otitis media	1	20				
386	Otosclerosis	2	4	140–209	Neoplasms	2	111
400–404	Hypertension	6	178	370–379	Refractive & other diseases of eye	26	113
410–414	Ischaemic heart disease	9	120	388–389	Other deafness	81	32
427	Congestive failure	4	55	N805–N949	Accidents	45	767
				Total	Four groups above	154	1023
				Grand total		285	2683

same people as were listed in the diagnostic index, for example, the general practitioner is the main source of referral of patients to the home nurse.

Conclusion

The experience described in this report suggests that the current notes, records and registers available within a general practice cannot be directly used for the location of all handicapped people among the population living within an administratively-defined community or among people registered with a general practice. The major problems in locating handicapped people among a general-practice population related to the diffuseness of definitions of handicap (Jefferys *et al.*, 1969; Bennett and Garrad, 1970; Sainsbury, 1973; Agerholm, 1975; Blaxter, 1975), the lack of recording either in the medical notes or registers of criteria used in defining handicap, and the lack of systematic up-dating of recorded information (Dawes, 1972; Hannay, 1972). This survey has shown that some records even in a practice participating in research and teaching are deficient in details about hearing ability, visual acuity, and locomotion; and this is not surprising as the records are kept mainly for the clinical handling of patients' problems and not the comprehensive care of disabled people.

An alternative method of locating and helping handicapped people registered with a general practice that might be investigated is the use by members of the primary care team (the general practitioner, the home nurse, and the health visitor) of a check-list designed to define whether a patient with whom they are in contact is handicapped and has needs that might be met by one or other of the statutory or voluntary agencies. The Office of Population Censuses and Surveys National Morbidity Study reported that 67 per cent of the practices' population consulted their doctors during the year, so that it would be necessary to mount a survey of the population that had not consulted by the end of the year. Such an approach would have the advantage of spreading the load of meeting newly discovered need over a reasonable period of time and could be adapted as a means of updating information.

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MEDICAL PRACTICE AREAS IN ENGLAND: SOME FACTS AND FIGURES

Existing policies to improve the geographical distribution of general practitioners are based upon the division of the country into *ad hoc* areas. These medical practice areas vary considerably in size and in the extent to which they follow other recognised boundaries. The size of practice areas is related to the patient: doctor ratios within them. Small areas are mostly classified as restricted (i.e. having low average list sizes) and larger areas are generally classified as designated or open. The optimum size of an area to reveal real variations in the accessibility of general practitioners is about 20 doctors, but some 60 per cent of unrestricted principals are in areas larger than this.

There is a considerable range in the average list sizes displayed by the four classes of practice area. Many areas have average list sizes outside the normal range for their classification. There is also a wide dispersion of individual list sizes within areas, and many practitioners have actual lists that are considerably at odds with the average for their area classification.

In order to monitor the effectiveness of distributional policies, statistics are needed of long-term trends in the movement of doctors to and from areas of relative shortages and surpluses. Existing statistics, being essentially snapshot pictures at single points in time, are inadequate to show time trends, and there are actually dangers involved in inferring flow trends from stock data.

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