YOUNG CHRONIC SICK

A survey reported for the Research Committee of the Scottish Council of the College of General Practitioners*

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Chronic ill-health is present in all age groups from birth, through childhood and adolescence into adult life. In later years, the natural processes of wear and tear aggravate diseases which may have been present since infancy and so the problems presented by chronic ill-health tend to become confused with those of old age, with the result that young people with a chronic disability may be found languishing in geriatric wards. In combatting this problem, such voluntary organizations as the Cheshire Foundation—with its Homes for young chronic sick—have helped some of the more distressing and obvious cases, but the bulk of such patients are at home. In this environment, the medical and social problems of both the patients themselves and their close relatives are the responsibility of the general practitioner, who is in the best position to know the special needs of individual cases.

It was felt that it would be helpful to use this knowledge to obtain information about the problems presented by younger people with chronic disabilities who are not resident in institutions. The present report is based on the opinions expressed, as part of a wider enquiry, by practitioners about some of the more urgent needs of the young chronic sick.

Source of Information

Members of the College in Scotland were asked to record on a *proforma* all patients under 35 years of age who were in need of medicosocial service. This information was based on the memory of the practitioners rather than on a systematic search through

*This survey was part of the evidence submitted to a working party of the Scottish Health Services Council. A list of those taking part is given at the end of the text.

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records. In this way it was hoped to obtain information about the problems which were uppermost in the minds of the doctors and therefore the most important in the home management of the young chronic sick.

The practitioners were asked to state the disease from which each patient was suffering and a suggested list of headings was offered. In addition, information was sought about the age of the patient, the degree of disability, and the service required.

Results

Members and associates from 24 practices co-operated and the combined population amounted to 90,500 patients. Half the practices were in large towns (total practice populations 62,600) and half the practices were in small towns or rural areas (population 27,900). The numbers recorded by practitioners showed wide differences, the rates varying from one young chronic sick per thousand population of all ages up to ten per thousand.

Two Edinburgh group practices, each with very full records and age-sex registers, had an aggregate of 186 young chronic sick out of a total of 24,500 registered patients of all ages (7.8 per 1000). The remaining practices together recorded 151 young chronic sick out of a total of 66,000 registered patients (2.3 per 1000).

In the case of the two group practices, the numbers under 35 years were subsequently found to total 15,938 (69.2 per cent of total practice population). For these practices the recorded total of 186 young chronic sick is equivalent to a rate of 11.7 per 1000 for that age group. Similar information for the other practices could not be obtained. It is known, however, that 53.8 per cent of the total population of Scotland is under the age of 35 years, so the practices quoted contained more than the average proportion of younger people.

The differences in rates of recording can be accounted for to some extent by the fact that those practices with special record systems did not have to rely solely on memory to obtain information for an enquiry of this kind.

Age distribution

The patients have been divided into three age groups—pre-school, school, and adult. Table I shows that 258 (80 per cent) out of a total of 337 patients were from large towns and cities. There

were 51 infants representing 15 per cent of the 337 recorded, and the proportion in the large towns differed little from that of the small towns and rural communities. Above the age of 5 years, however, the ratio of school children to adults under 35 years recorded as being disabled, and in need of social services, was 1 : 3 (58 : 160) in the large towns whereas the ratio of those recorded was 1 : 1 (33 : 35) in the other practices. The difference is significant ($p < 0.01$), but interpretation of the observation calls for caution, since the age structure of the two populations is unknown.

TABLE I
AGE AND SEX OF PATIENTS RECORDED BY THE FAMILY DOCTORS

Age in years	*Large towns*	*per cent*	*Small towns and rural*	*per cent*	*All practices*	*per cent*
0—	40	*15·5*	11	*13·9*	51	*15·1*
5—	58	*22·5*	33	*41·7*	91	*27·0*
15—35	160	*62·0*	35	*44·3*	195	*57·9*
All ages under 35 (on which percentages are based)	258		79		337	

Morbidity pattern

The commoner diagnoses which were recorded by practitioners as causing chronic disability in patients under 35 years of age have been listed in table II. Where possible, the dominant condition only was recorded, but two disabilities were present in 26 (7.8 per cent) out of a total of 337 patients; half of these 26 patients were male. The commonest cause of chronic disability in both males and females was chronic pulmonary disease (excluding tuberculosis) followed by epilepsy and chronic heart disease. Thus the young asthmatic child or wheezy infant who develops later into the respiratory cripple presents its challenge to preventive medicine. Arthritis and malignant disease, which play such a dominant roll among the chronic disabilities of later life, were only of limited importance below the age of 35 years.

The need for services

The unfulfilled needs for services are greater in the small towns and rural areas than in the large towns. Table III shows the services which the general practitioners thought should be supplemented; with the exception of sheltered employment all the needs are

TABLE II

CLASSIFICATION OF DISEASES IN 337 YOUNG PATIENTS

Diagnosis	*Number of patients*	*Rate per 100,000 registered population (of all ages)*
Chronic pulmonary disease (excluding T.B.)	64	71
Epilepsy	43	48
Chronic heart disease (including congenital)	30	33
Spastics	24	27
Mental deficiency of unspecified aetiology	21	23
Deafness	19	21
Chronic skin disease	15	17
Arthritis	14	16
Malignant disease (including leukaemia, etc.)	12	13
Thyroid disease	12	13
Poliomyelitis (late effects of)	11	12
Diabetes	10	11
Blindness	10	11
Dyspepsia and ulcers	8	9
Multiple sclerosis	8	9
Other congenital defects (unspecified)	31	34
All other disabilities	33	37
Patients with more than one disability	26	29

proportionately greater for patients away from the large towns. This exception must be considered along with the high need for rehabilitation and home employment, which was stressed by the rural practitioners. Some such facilities are already present in the large towns and young patients with chronic disabilities stand a better chance of getting back to productive employment if the employers in question will make allowance for irregular attendances.

Discussion

The parents of young people with a chronic disability may be reluctant to discuss their problem in public because of fear that the community will attach to the parent some degree of blame for the ill-health of the off-spring. Problems do exist, however, and there is a desire to have these ventilated. This is evident from the recent increase in the number of societies which offer facilities for patients

TABLE III

NEED FOR SERVICES

Service	*Large towns per cent*	*Small towns and rural per cent*	*All recorded needs per cent*
Education	11·2	17·7	12·8
Rehabilitation	3·5	20·6	7·4
Employment at home or special centres	4·3	8·9	5·6
Physio. and occup. therapy ..	5·4	15·2	7·7
Housing	9·3	12·7	8·9
Sheltered employment ..	22·4	17·7	21·1
Need for transport	8·9	19·0	11·3
No service needed	39·5	24·2	35·9
Young chronic sick (under 35 years) on which percentages are based	258	79	337

(Needs are not mutually exclusive).

and their relatives to meet and discuss problems of mutual interest. These groups usually carry the name of a disease or group of diseases, and understandably they devote much of their efforts to publicizing the problems presented by their own disability.

The information recorded in this report does not include all young persons with chronic disabilities in the practices covered. It seems likely, however, that the patients who are remembered and whose needs are recorded are the ones who have been causing anxiety, and for whom the doctors feel that more should be done.

Information about patients suffering from mental illness and mental backwardness was not specifically requested, as a more detailed survey of this was being planned and has since been carried out separately. Thus it is likely that the number of those with mental illness in particular has been under-recorded.

Exact comparisons with previous studies are not possible since reports which specialize in one aspect of disease are usually written

by workers with particular interests in small groups of closely related illnesses.

Logan and Cushion (1958) when working with the College of General Practitioners, compiled tables based on morbidity studies in general practice, but these gave the overall prevalence rate of disease without differentiating those patients in whom a chronic illness was associated with social problems. Where the diagnoses in the present study were reasonably precise (i.e., epilepsy and diabetes) it would appear that the practitioners have recorded about one seventh of the total patients who might be expected to consult them for these conditions during the course of a year.

The wide range of prevalence rates for young chronic sick given by the different practitioners may be caused by different age structure from practice to practice, but it could also be a reflection of the different interests of the practitioners concerned.

In spite of these drawbacks, there is little doubt that this type of enquiry can best be carried out in the setting of family medicine since the needs are so often related to the family as a whole. The figures quoted can only be regarded as minimal, and since they refer mainly to unfulfilled needs of an urgent nature, it would seem to be advisable to seek more detailed and specific information from a few selected practices. Those with age-sex registers are best suited to this type of work and a clearer concept of the services required would also be helpful.

Summary

1. A list of patients under the age of 35 years with chronic illness resulting in unfulfilled medical social needs has been compiled from general practice sources. The overall prevalence of those with urgent needs is 3.7 per 1,000 of registered patients of all ages.

2. The relative prevalence of disease in causing such needs indicates that non-tuberculous respiratory disease and epilepsy are of major importance. Mental illness is not discussed here, and is part of a separate study.

3. The suggested requirements for young chronic sick have been listed. Sheltered employment in the town and rehabilitation services and transport in the rural areas are the most important.

4. The limitation of such an enquiry and possible methods of clarifying the information are discussed.

The following members and associates of the College took part in this enquiry:

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L. Blair, Glasgow
A. Clarke, Glasgow
R. C. Fergusson, Lochinver
J. A. Fraser, Glasgow
W. A. Gardener, Glasgow
D. A. Hamilton, Kincardine
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J. Paterson, Orkney
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J. C. Reid, Strathdon
J. S. Scribler, Glasgow
M. Scott, Stonehaven
W. E. Smith, Inverness
J. N. Walker, Edinburgh
J. E. C. Waterson, Lochininnoch
J. Watson, Dumfriesshire
H. Younger, Hawick

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EXAMINATION FOR MEMBERSHIP

During the year we were visited by Dr Loudon and Dr Gibbons, Nuffield Fellows, who were shown around and entertained by the board, and we listened to an able address from Dr Gibbons on his impressions of practice elsewhere.

In February, Dr George Swift of the College Council passed through Auckland on his way south, and at the meeting in Dunedin he sought an expression of opinion as to the desirability or otherwise of an examination for membership. The attitude of this faculty is, I think, fairly well summed up by saying that we do agree that such an examination is ultimately necessary, but that the form and content of such an examination requires much thought and that the problem of active continuing membership, together with the possible loss of the present admirable *esprit de corps*, occasions us considerable anxiety. The College is, after all, the sum of its parts and it stands or falls by the quality and interest of its members and the interest displayed by them in its affairs.

The form and content of general practice is a proper concern of the College, and likewise any politically inspired changes which may have an adverse effect on standards of practice are legitimately our concern. I am convinced that there is a need for a forum in the faculty and, for that matter, within the College itself in New Zealand, and feel most strongly that we cannot afford to let things drift in this matter.

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