

Comparison of the care of children with Down's syndrome with the care of matched controls

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SUMMARY. A prospective study of the care of 134 children with Down's syndrome and 134 age- and sex-matched control children during 1981 has shown that the former group had significantly greater contact with the general practitioner, mostly owing to respiratory problems which were treated significantly more often with antibiotics. Referrals to specialist care were more common in the Down's children but the interface between general practice and paediatric care was not great. The study emphasizes the need for general practitioners to plan the care of Down's children and normal children with respect both to acute illness and the monitoring of chronic childhood illness.

Introduction

Although Down's syndrome is the most common recognizable cause of mental handicap in children in the UK, it has a relatively low prevalence, estimated in Scotland to be 5.2 per 19,000 in girls (0-14 years of age) and 6.6 per 10,000 in boys.¹ This provides one reason why it is unlikely that any general practitioner could acquire the necessary expertise in the primary care of such children from personal experience. Another reason is that Down's syndrome individuals demonstrate physical vulnerabilities, interpretation of which is complicated by the presence of mental handicap.

There have been few studies from general practice of children with handicap. The studies that have been done refer to handicap of such widespread aetiology that they are difficult to interpret.^{2,3} This study was specifically designed to compare the care of Down's children with the care of children of normal intelligence and chromosomal content during 1981.

Patients and methods

Details of 146 children with Down's syndrome aged between one and 10 years, living at home with both parents, were

Table 1. Age and sex distribution of Down's children and control children.

Year of birth	Down's children			Control children		
	Male	Female	Total	Male	Female	Total
1971-72	14	7	21	15	6	21
1973-74	14	15	29	14	14	28
1975-76	18	13	31	18	14	32
1977-78	14	10	24	14	10	24
1979-80	13	16	29	14	15	29
Total	73	61	134	75	59	134

obtained through a survey of all general practices in Scotland.¹ The general practitioner of each child was asked to select the next child in date order either from an age-sex register or from the practice files who was matched for age, sex, social class and family size.

The records of both children and their parents were then clearly marked and at each contact details were entered in a morbidity register. The details recorded for each contact were: date; new or return contact; home or surgery; problem(s); drugs prescribed; referral made to inpatient or outpatient, with speciality involved.

The morbidity registers were returned centrally and the problems were coded according to the *International classification of diseases (ICD)*. Drugs were coded according to the Department of Health and Social Security *Drug master index*.

Results

One hundred and eight general practitioners participated in the study and full data for the year were received on 134 pairs (92 per cent) of children, whose age and sex distribution is shown in Table 1. The mean age of the mothers of the Down's children at 1 January 1981 was 36.4 years compared with 32.3 years in control mothers. Mean paternal ages were 38.5 years and 34.9 years for the Down's children and controls respectively. Forty eight (36 per cent) of the Down's children had congenital heart disease (CHD) of varying degree while only one of the control children was so affected. Chromosome analysis on the whole group of 146 Down's children revealed a positive result in 111 cases (76 per cent). Of these, 99 (89 per cent) were standard trisomy, six (5 per cent) 14/21 translocation, four (4 per cent) 21/21 translocation and two (1 per cent) mosaicism. In the remaining 35 cases chromosome studies were not recorded.

Table 2. Contacts of Down's children and controls with general practitioners in 1981.

Group	Number	Any contact (percentage)	Mean contact per patient		
			Total	Home	Surgery
Down's children	134	122 (91.0)	5.6*	1.2	4.4
Control children	134	104 (77.6)	2.6*	0.4	2.2

*Down's children v. controls — highly significant $P < 0.01$ (McNemar's test).

Workload and place of contact

The contacts with the family doctors of the Down's children and controls are shown in Table 2. The children with Down's syndrome were seen by the general practitioner in his surgery twice as often as controls (5.6 v. 2.6) and at home three times as often as controls; 91 per cent of the Down's children were seen at least once in the course of the year by the general practitioner, compared with 77.6 per cent of controls.

Problems encountered

New and repeat problems presented to the doctor were recorded at each contact. Classification of the problems presented by the children over the course of the year are shown in Table 3 by ICD groupings, where the total was 10 or more. The Down's group presented 4.3 new and 2.1 repeat problems per patient, while the control children presented 2.2 new and 0.7 repeat problems per patient. Respiratory problems comprised the largest category of illness in the Down's group and in the control group, and this finding will be discussed in detail below. However, infectious diseases, eye problems, behaviour problems, digestive problems, skin problems and symptoms were also much more frequent in the Down's children.

Prescribing

Drugs were prescribed at 546 (72 per cent) of the consultations with the Down's children and at 240 (70 per cent) of the consultations with the control children. Prescribing reflected the diagnoses quoted above and classification of the total prescribing is in Table 4. A total of 674 items were prescribed to the Down's children and 283 items to the control children. Antibiotics were by far the most common group of drugs prescribed.

Management of respiratory illness

Table 5 shows the incidence of new episodes of respiratory illness and those which were treated with antibiotics. The proportion of respiratory problems in the Down's children treated with antibiotics was significantly greater than those occurring in controls ($\chi^2 = 8$, $P < 0.01$),

Table 3. Number (percentage) of new and repeat problems presented by Down's children and control children during 1981. (Problems involving less than 10 contacts have been omitted.)

ICD class	Down's children		Control children	
	New problems	Repeat problems	New problems	Repeat problems
Infective	51 (9)	22 (8)	27 (9)	6 (—)
Mental	17 (3)	16 (5)	7 (—)	8 (—)
Eyes	44 (8)	11 (4)	14 (5)	1 (—)
Ears	29 (5)	11 (4)	28 (9)	17 (18)
Respiratory	262 (46)	98 (34)	98 (33)	26 (27)
Gastrointestinal	24 (4)	9 (—)	9 (—)	3 (—)
Dermatological	22 (4)	6 (—)	16 (5)	3 (—)
Congenital	2 (—)	26 (9)	1 (—)	— (—)
Symptoms	76 (13)	63 (22)	58 (19)	21 (22)
Accidents	30 (5)	12 (4)	32 (11)	6 (—)
Total	573 (100)	288 (100)	300 (100)	96 (100)

Table 4. Classification of drugs prescribed to Down's children and controls during 1981.

Drug group	Down's children (percentage of total)	Controls (percentage of total)
Antibiotics	331 (49)	114 (40)
Expectorants	57 (8)	18 (6)
Vaccines	49 (7)	41 (14)
Vasoconstrictors (nasal drops)	32 (5)	11 (4)
Psychotropics	21 (3)	5 (2)
Antihistamines	17 (3)	14 (5)
Laxatives	17 (3)	9 (3)
Antidiarrhoeals	17 (3)	1 (—)
Corticosteroids (incl. topical)	15 (2)	9 (3)
Analgesics	13 (2)	15 (5)
Cough suppressants	12 (2)	7 (3)
Diuretics	11 (2)	0
Vitamins	11 (2)	0
Various other groups	71 (10.5)	39 (15)
Total	674 (100)	283 (100)

most of this being accounted for by the significantly greater proportion of Down's patients with the diagnoses of coryza, cold or catarrh, who were treated with antibiotics. It is of interest that over 60 per cent of the controls with any respiratory problem were treated with antibiotics.

Referrals to specialist care

A summary of the care of the two groups of children is shown in Figure 1. Thirty-three (25 per cent) of the Down's children and 13 (10 per cent) of the control children were referred for specialist care over the year. The Down's children had a total of 55 referrals of which 41 were for outpatient attendance only. The most common referrals were to ear, nose and throat (ENT) departments (mainly for hearing difficulties), and

Table 5. New respiratory problems presented in 1981 by Down's children and controls with number (percentage) treated with antibiotics.

Problem	Down's children		Controls	
	Number of episodes	Treated with antibiotic	Number of episodes	Treated with antibiotic
Coryza, cold, catarrh	24	11 (46)	15	1 (7)
Pharyngitis	12	10 (83)	9	8 (88)
Tonsillitis, enlarged tonsils	27	27 (100)	19	14 (74)
Rhinitis	5	2 (40)	—	—
Sinusitis	1	1 (100)	1	1 (100)
Upper respiratory tract infection	107	69 (65)	31	16 (52)
Laryngitis	—	—	—	—
tracheitis	6	5 (83)	3	2 (67)
Acute bronchitis	17	17 (100)	5	5 (100)
Chronic bronchitis	5	5 (100)	2	2 (100)
Asthma	—	—	3	2 (67)
Chest infection	55	49 (89)	7	7 (100)
Influenza	—	—	3	—
	259	196 (75.7)*	98	58 (59)*

* $\chi^2 = 8.63$; $P < 0.01$.

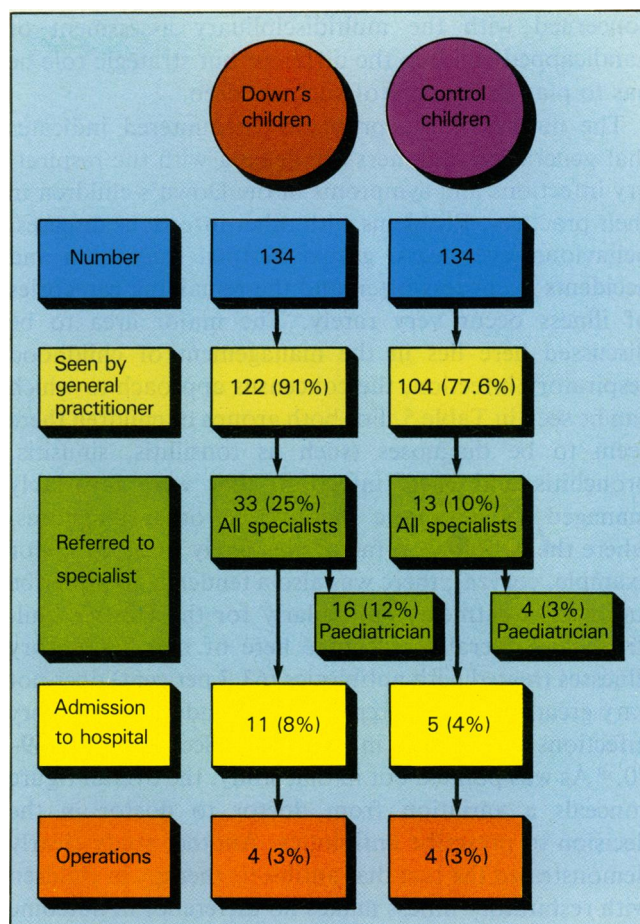
routine paediatric appointments for developmental assessment. Of the 14 admissions to hospital, five were arranged and nine were acute admissions (five cases of chest infection, two convulsions, one case of haemophilus meningitis and one of aggressive behaviour). Four Down's children had operations, all arranged (three were tonsillectomies and one was for undescended testis). None of the 134 Down's children died in the course of the year.

Of the controls, there were nine outpatient referrals, six inpatient admissions, of which three were arranged (two tonsillectomies and one excision of a cyst on penis) and three were acute (nonaccidental injury, chest infection and acute asthma). There were four operations, all arranged (three tonsillectomies and one excision of cyst on penis), and again no child died during the year.

Discussion

There has been much recent controversy about the care of children in general practice⁴ and the role of the general practitioner in paediatric screening. The general practitioner's role has to be considered in two other main areas: in the management of acute childhood illness and in the monitoring of chronic childhood illness.⁵

A recent review of child care in general practice⁶ has pointed to the comparative lack of evidence with respect to the management of acute childhood illness in general practice. The data presented here were returned from

**Figure 1.** Flow diagram of care of Down's children and control children over the course of the year (1981).

110 of the 1,136 practices in Scotland and contributes virtually a 10 per cent sample of the actual care given to children in general practice in 1981. The overall consultation rate per patient per year (controls) was 2.6 compared with 2.8 in the second national morbidity study,⁷ while that for respiratory illness was 0.92 compared with 0.96 in the morbidity study. The contact rates in controls are much lower than the 4.2 per patient per annum reported in studies of the 0-2 years age group⁸ or the 4.5 per patient per annum reported in the 0-10 years age group.³ Another comparison can be made with a study in Aberdeen of socially deprived children⁹ where the annual consultation rate in 139 such children was 4.3.

The figures of workload reveal that general practitioners saw the majority of the child patients over the course of the year and, in particular, they saw those children with Down's syndrome. Twenty per cent of the contacts with the latter were in the patient's home as were 15 per cent of the contacts with control children.

This amount of contact emphasizes the continuing role of the general practitioner as the personal and family physician and should demonstrate to those

concerned with the multidisciplinary assessment of handicapped children the different but strategic role he has to play in the care of such children.

The nature of the problems encountered indicates that general practitioners are dealing with the respiratory infections and symptoms in the Down's children in their practices. Problems with other infectious diseases, behaviour, eyes, ears, gastrointestinal tract, skin and accidents occur less often and the remaining categories of illness occur very rarely. The major area to be discussed here lies in the management of childhood respiratory infection, the consensus approach to which can be seen in Table 5. For both groups of children there seem to be diagnoses (such as tonsillitis, sinusitis, bronchitis and chest infection) that were invariably managed by antibiotic therapy; in other diagnoses, where the aetiological factor was likely to be viral (for example, coryza), there was also a tendency to prescribe antibiotic treatment, particularly for the Down's children. The overall percentage here of new respiratory illnesses treated with antibiotics (63.7 per cent) does not vary greatly from that reported in a study of respiratory infections carried out in north-east Scotland in 1969-70.¹⁰ As was pointed out in that study, the overall figure conceals a variation from doctor to doctor in the decision to prescribe antibiotics. Another study clearly demonstrated the fact that antibiotic therapy in children with respiratory illness makes no difference in outcome with respect to complication rates, return rates and reinfection rates.¹¹ It is interesting to speculate why it is that general practitioners have not been influenced by this evidence and why antibiotics continue to be 'over-prescribed, to the detriment of the environment, the patient's expectations and the person who foots the bill'.¹²

The comparison between Down's children and control children does reveal that the same doctor prescribes significantly more antibiotics for new respiratory infections in the Down's child than he does for the control child. A previous study of antibiotic prescribing for respiratory illness in children has shown that the children of mothers with a high use of psychotropic drugs were given significantly more antibiotics than the children of mothers with low or no use of psychotropic drugs.¹³ Another study by this author has shown no significant difference in the presentation of psychological problems in the mothers of the children in the present study.¹⁴

Therefore, the hypothesis for the greater antibiotic prescribing here is anxiety created by the handicapped child rather than his mother, and it is interesting to speculate on the relative part played by the frequency of consultation and the known increased mortality of respiratory illness in Down's syndrome in the decision to prescribe in this way. The drug classification in Table 4 shows that antibiotics, expectorants, vasoconstrictors, antihistamines, analgesics and cough suppressants together account for no less than 69 and 63 per cent of

the total prescribing for the Down's children and control children respectively.

The significantly higher rates for consultation and presentation with respiratory illness in the Down's children draws attention to the special needs of these children within general practice and the need for the monitoring of their chronic illness.

The reason for the higher workload created by these children is not clear. The first possible reason is a greater susceptibility to infection in the Down's children. A Swedish study demonstrated much higher mortality rate in a group of children with Down's syndrome in this age group and stated that the main cause of death was congenital heart disease and respiratory tract infection.¹⁵ A Danish study has shown an overall death rate in the Down's syndrome population to be five to seven times that of the general population rate, with the excess mortality being especially high for heart and respiratory disease.¹⁶ The theoretical basis for this higher susceptibility to infection lies in the altered cellular immune functions in Down's syndrome patients^{17,18} and the defective response to adrenocorticotrophic hormone stimulation by the adrenal cortex.¹⁹ The fact that a particular individual also had congenital heart disease might contribute to the higher morbidity, and a study of this factor will be considered in a separate study.

It is also possible that family and maternal anxiety with respect to the child's handicap might alter the help-seeking behaviour in these mothers and induce an artificially high consultation rate which may be interpreted as a higher morbidity rate. This possibility is reinforced by study of the illnesses which were referred on to specialist care. The fact that during the year only four Down's children were admitted to hospital with respiratory problems, one child with epiglottitis previously reported,²⁰ hardly points to a burden of serious respiratory illness. A further possibility is that doctor anxiety might induce mothers to bring their children back more often.

Even allowing for the possibility that many of the Down's children might have been already attending hospital assessment clinics, and these were not recorded as referrals, the extent of the interface between general practice and hospital care in this study is not great. Many more, that is 33 (25 per cent), of the Down's children were referred to specialists in the course of the year than the control children but in only 16 of these cases (12 per cent) was the referral to a paediatrician.

Referrals for otorhinolaryngological examination were the most common and perhaps should be more common in view of the evidence provided by a recent study showing a prevalence of deafness in Down's children of 70 per cent, mainly as a result of serous otitis media.²¹ With respect to this risk, it is of particular concern that ear problems were not recorded more frequently in the Down's children in this study.

The main conclusion from this study is that the

general practitioner is seeing most of his child patients in the course of a year and almost all of his Down's syndrome patients. His position, and that of his health visitor associate, is therefore a strategic one with respect to both groups of children. In short, he is a paediatrician but one whose task has little in common with the paediatrics specialist. It is vital that channels of communication be opened so that the role of the general practitioner in the care of the handicapped child can be strengthened rather than ignored by his specialist colleagues. It is suggested that this can be done in two ways.

First, the content of his education for this task requires to be fundamentally different from that currently taught by university departments of child health, and both undergraduate and postgraduate training must take this factor into account as has been done in some centres.^{22,23} A second consideration is the planning of health care delivery in general practice to special groups such as the Down's syndrome child. There are special risks to this child in terms of susceptibility to infection, deafness and thyroid deficiency,²⁴ about which his general practitioner should have knowledge. Dealing with the Down's child and his family calls for communication and diagnostic skills that are higher than those for other children. In his attitudes the general practitioner has to be aware of the special needs of a family in which one child is fundamentally different from others around him. It is in these circumstances that the most fundamental feature of training for general practice will be tested—an open mind, a willingness to learn from the family and from those who have made a special study of Down's syndrome, and a commitment to the highest possible achievement for the child and for the whole family.

Can we assume that the general practitioner will be equal to this task? Court, in a review of the RCGP report *Healthier children—thinking prevention*,⁴ called for the accurate monitoring of chronic childhood illness and remarked that, in practice, its implementation is still the exception rather than the rule.⁵ Surveillance of Down's children in general practice is particularly essential in view of the serious risks faced by such children. Poor surveillance may be causing needless handicap. It is not enough to plead excuse on the grounds of the rarity of Down's syndrome and the fact that there would be handicap in any case. The primary care of mental handicap requires knowledge, skills and attitudes such that if surveillance were not possible within the present structure, a case could be made for a 'mental handicap/rare syndrome' list, which, like the obstetric list, would require fuller training and experience of eligible general practitioners on whose list such children and their families would be registered. Such a system might be seen to be dictatorial but it would be no more so than the present one, which dictates that such children should be at risk of further handicap through the ignorance of their family doctor.

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