Down's syndrome children and parental psychological upset

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SUMMARY. A prospective morbidity study of the parents of Down's children and the parents of control children matched for age, sex, family size and social class failed to demonstrate any difference in the incidence of psychosis, psychoneurosis or self-poisoning referred to the general practitioner. It is suggested that the common assumption that Down's syndrome and parental anxiety are inevitably associated is questionable.

Introduction

THE BIRTH of a handicapped child such as a child with Down's syndrome is an event which produces significant emotional upset in both parents. Several workers have emphasized the need to counsel such parents in two ways—by advising them to mourn the loss of a normal child and to adapt to the fact that they have an abnormal child whose appearance and significance is stressful both to them and their professional advisers.[1,2] The acknowledgement that such an experience is emotionally traumatic is, however, not an admission that stress and psychological upset is to be a permanent feature of the life of such a family. This study sought to compare the mothers and fathers of Down's syndrome children and control children of the same age in terms of psychological upset in the two groups.

Method

One hundred and forty-six children with Down's syndrome who were between the ages of one and 10 years and living at home in Scotland were identified.[3] No attempt was made to study one-parent families since of 323 children with Down's syndrome only 25 children living with one parent were found.

The general practitioner of each child was asked to select a child without Down's syndrome of the same sex, and matched for social class and family size. The control child was to be the nearest in date of birth to the Down's syndrome child on the age-sex register, if available, or otherwise the nearest candidate on the alphabetical file who was born in the same year as the Down's syndrome child.

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The records of mothers and fathers of Down's children and control children were scanned for history of illness before conception, and from conception to 31 December 1980. In particular, information was sought on any history of psychosis, psychoneurosis and self-poisoning (ICD codes 296.0-308.0 and 977.9). A prospective study was carried out during 1981, and overall contact rates and presentation of psychological problems were recorded.

Results

Full data was found for 138 pairs of mothers and 131 pairs of fathers (in seven cases the father was a patient of another doctor). The mean age of mothers of Down's syndrome children on 1 January 1981 was 36.4 years compared with 32.3 years in the control mothers, and 38.5 years and 34.9 years in fathers of Down's syndrome children and controls respectively.

Psychological problems before conception of study child

Nineteen (13.8 per cent) of the mothers of Down's syndrome children and eight (5.8 per cent) of the mothers of control children had a history of psychological illness or self-poisoning before conception of the study child. The difference in the mothers' histories was significant ($P < 0.05$, McNemar's test). Out of the 138 pairs, there were three pairs where both mothers had a history of psychological illness or self-poisoning and 21 pairs where the mothers had dissimilar histories of psychological illness; thus there was a history of problems in 24 of the pairs. Six (4.6 per cent) of fathers of Down's syndrome children and four (3.1 per cent) of the fathers of controls had a history of psychological illness or self-poisoning. The difference was not significant. The history of problems was similar in one of the pairs of 131 fathers and dissimilar in eight of the pairs; thus there was a history of problems in nine pairs.

Psychological problems since conception of the study child

Table 1 shows the recorded incidence of psychological problems in parents of Down's syndrome children and

Table 1. Incidence of psychological problems in parents of Down's syndrome and control children where no previous history of problems was present in either pair before birth of child.

Year of birth of child	Parents with no previous psychological problem (number of pairs)	Occurrence of psychological problems in parent pairs between 1971 and 1980 (number of pairs)			Incidence of problems per year (% per annum)		95% confidence limits for difference in incidence (% per annum)
		Parent of Down's child	Parent of control child	Both parents	Parent of Down's child	Parent of control child	
Mothers							
Between 1971 and 1975	57	6	6	4	2.2	2.2	
Between 1976 and 1980	57	5	3	2	4.1	2.9	
Total (between 1971 and 1980)	114	11	9	6	2.8	2.5	*(−1.1, 1.9)*
Fathers							
Between 1971 and 1975	58	2	1	0	0.4	0.2	
Between 1976 and 1980	64	3	2	0	1.4	1.0	
Total (between 1971 and 1980)	122	5	3	0	0.7	0.4	*(−0.5, 1.1)*

Table 2. Incidence of psychological problems in parents of Down's syndrome and control children where no history of psychological problems was present before 1981.

	Number of pairs	Occurrence of psychological problems in parent pairs in 1981 (number of pairs) (% per annum)			95% confidence limits for difference in incidence (% per annum)
		Parent of Down's child	Parent of control child	Both parents	
Parents with no history of psychological problems before 1981					
Mothers	88	6 *(6.8)*	12 *(13.6)*	0	*(−16.4, 2.8)*
Fathers	114	7 *(6.1)*	2 *(1.8)*	0	*(−0.9, 9.6)*
Parents with no history of problems before birth of child					
Mothers	114	12 *(10.5)*	14 *(12.3)*	4 (3.5)	*(−10.7, 7.2)*
Fathers	122	10 *(8.2)*	4 *(3.3)*	0	*(−1.2, 11.1)*

control children, excluding the 24 pairs of mothers and the nine pairs of fathers in which either one or both members of the pair had a previous history of psychological problems. Because the mothers had given birth between one and nine years before the prospective study, the incidence of illness was calculated separately for mothers of children born between 1971 and 1975 and between 1976 and 1980 by dividing the number of cases by the 'person-years at risk' between the conception year and the year 1980.

The 95 per cent confidence limits for the difference in proportions of parents experiencing problems[4] are shown in Table 1 after they were divided by the mean years at risk, thereby indicating a range within which the true difference in incidences might reasonably lie.

There was no significant difference between the incidence of psychological problems in either mothers or fathers of Down's syndrome children in the periods 1971 to 1975 or 1976 to 1980, or during the whole period 1971 to 1980.

Psychological problems during 1981

Table 1 shows that, of the 114 pairs of mothers with no psychological problems before the birth of their child, a further 26 pairs developed psychological problems after the birth of the child leaving 88 pairs of mothers with no history of problems before 1981.

Of the 122 pairs of fathers with no problems before the birth, eight pairs developed problems between 1971 and 1980 leaving 114 pairs with no problems before

Table 3. Contact rate in 1981 for psychological problems and all problems in 138 pairs of mothers and 131 pairs of fathers.

Status of child	Mean number of contacts per patient per year	Number of contacts for psychological problems (%)	Number of contacts for any problem (%)	95% confidence limits for difference in incidence (% per annum)
Mothers				
Down's syndrome	3.9	25 (*18.1*)	103 (*74.6*)	*(−9.3, 7.8)*
Control	3.8	26 (*18.8*)	112 (*81.2*)	
Fathers				
Down's syndrome	2.1	11 (*8.4*)	89 (*67.9*)	*(−1.5, 10.7)*
Control	1.8	5 (*3.8*)	75 (*57.3*)	

1981. Table 2 shows the number of pairs of parents suffering psychological problems during 1981. The control mothers showed rather higher incidence than the Down's syndrome mothers, but the difference was not significant. The Down's syndrome fathers showed a higher incidence than the control fathers, but again the difference was not significant. Table 2 shows similar comparisons based on parents with no illness before conception.

Total problems during 1981

The full pattern of morbidity in the whole population of 138 pairs of mothers and 131 pairs of fathers is shown in Table 3. The overall picture is of a similar mean contact figure per patient per year for Down's syndrome and control parents, more mothers than fathers contacting the doctor for any reason and a similar incidence of psychological problems in Down's syndrome mothers and control mothers. The incidence of psychological problems in fathers was greater for Down's syndrome fathers, but the difference was not statistically significant.

Discussion

This study was designed to compare the incidence of psychological problems in previously healthy parents of Down's syndrome children with that in parents of normal children, as measured by the parents' presentation to the general practitioner. The fact that a significantly greater number of Down's syndrome mothers had a history of psychological illness before the child was conceived is of interest, particularly since it has been suggested that emotional stress before conception might be a cause of the trisomy.[5] However, it may simply be that such mothers and their doctors have their memory enhanced by the trauma of the experience.

Given the differences in psychological health of the parents before conception, there was no evidence of any difference in the incidence of psychological illness between the two groups. This was true for the variable retrospective period before the start of the prospective study and during the year of that study, although our small sample size meant we could not completely exclude the possibility of a difference. It is of considerable interest that the incidence of psychological problems during the prospective study was much greater than that in the preceding period, demonstrating the value of such prospective studies.

It is likely that reporting will be more complete and accurate in the case of the 1981 events than for events before 1981 for which the data was gathered retrospectively; this is supported by the incidence figures which show that recorded incidence is much higher for 1981 when data was obtained prospectively than for previous years when data was obtained retrospectively. Provided this bias is similar for all women, this should not invalidate comparisons between parents of Down's syndrome children and control parents, where the pairs are matched for date of birth of child. If it were true that reporting was better for Down's syndrome parents than for control parents, the Down's syndrome parents would be expected to show consistently higher incidences.

Our results fail to confirm the findings of Gray[6] and Bain,[7] who demonstrated increased psychiatric morbidity in the parents of handicapped children. Our study differed from these studies in that it dealt exclusively with Down's syndrome children and their parents and was specifically designed on a multi-observer basis with randomly selected controls. Bain quoted a contact rate of 6.4 per annum for all 3,559 mothers; 30 per cent and 22 per cent respectively being psychiatric consultations. In our study, the overall contact rate among Down's syndrome mothers was similar to that for controls; 3.9 contacts per annum with a standard error of 0.3.

Careful study of the Bain's data on handicapped children[7] revealed that 170 of the 349 patients (48.7 per cent) suffered from behaviour disorder or enuresis, conditions which may have their causes in maternal psychiatric morbidity. Gray[6] compared 80 handicapped children with control children in his practice and looked at the incidence of several factors in the respective

families: limitations of family size, moving house, transfer from a general practitioner in the same area, severe marital disharmony and parental psychological disorders. He demonstrated greater numbers of the above factors in the families with handicapped children but only for one factor—limitation of family size—was the difference significant ($P < 0.05$). Again, his definition of handicap was so wide-ranging that marital disharmony might have been an aetiological factor. Both these studies demonstrated the considerable difficulties of studying the family with handicap, and the danger of assuming that all handicaps involve similar risks to family stability.

In the present study, which refers only to families with a Down's syndrome child, there might be other factors accounting for the similar incidence of psychological illness in the two groups. The parents of Down's syndrome children were older than the controls, but as psychological problems tend to increase with increasing age this observation does not affect the conclusions. It might also be argued that the Down's parents were reluctant to admit to having psychological problems to their doctor, but this is unlikely to be relevant in view of the similar overall rates of contact.

The most valid conclusion from this study challenges the commonly held view that the birth of a Down's syndrome child leads to increased psychological morbidity. The important implication of such a finding is in the encouragement it might give to new parents, and to those who counsel them, that conceiving, bearing and bringing up a child with Down's syndrome carries no more stress than for a normal child. Although the newborn child with Down's syndrome faces real difficulties, many of them can be overcome by a positive approach in his medical advisers and above all in his parents. Perhaps in view of this evidence we can overcome an imaginary hurdle which has served to demotivate both parents and the counsellors of parents.

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