Mongolism: When Should Parents be Told?

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The practitioner responsible for the care of a handicapped child or an infant with a congenital defect has to decide what to tell the parents and when. In the event of physical defect of a visible nature some explanation must be given at once. Although the mother may be newly delivered and one might wish to spare her the knowledge of her baby's abnormality, it is hardly possible to conceal the fact of such congenital defects as cleft-lip, talipes, or spina bifida. In the case of mongolism, the only common category of severe mental defect which is recognizable at birth, the situation is different in that it may not be obvious to the parents that the infant is abnormal.

There is considerable disagreement about the best time to tell the parents of a mongol that their infant will be mentally handicapped. Some hold that, since the diagnosis and prognosis are not in doubt, the parents have a right to be told at once or as soon as the mother has recovered from the immediate effects of the confinement. Others maintain that acceptance of a handicapped child and adjustment to the fact of mental defect is facilitated if, in the early months at least, the parents are left in ignorance and the mother is allowed to make a normal loving attachment to her baby. This argument presupposes that the mother herself will not recognize her child's abnormality and also that her medical attendants will be able to act in such a way that her suspicions are not aroused. In some cases there will be definite reasons, known to the obstetrician or family doctor, for delay in telling the parents, but in general whether or not the mother is told early depends on the usual practice of a particular doctor or hospital.

Present Study

A current aetiological study of severely subnormal children in Edinburgh has provided the opportunity of questioning mothers of mongols about their attitude to the time at which they were first told of their child's defect. The total group of 239 includes all those children born in the years 1950–6 with intelligence quotient levels of less than 60 whose mothers are at present resident in Edinburgh. Of this number, 71 are mongols. The mothers of 70 were visited at home and interviewed by a health visitor with considerable experience in dealing with parents of handicapped children. The one mother not visited is unmarried and at the time of the investigation was herself in a mental hospital. Most of the children were born in Edinburgh, but there was no indication that the experiences of mothers delivered in other areas of Scotland or England differed in any way.

Each mother was asked when and by whom she was first told that her child was a mongol; whether she would have preferred to be told sooner or later, with the reasons for her preference, and whether she had any other criticisms about the time or method of telling. In the case of children born in or referred to Edinburgh hospitals we were usually able to check when the parents had been told. The information given by the mothers agreed substantially with that obtained from hospital records. In spite of the subjective nature of the information obtained it seems reasonable to suppose that if a majority of mothers told at a certain time later express satisfaction at the time chosen, while a majority of mothers told at a different time express dissatisfaction, this is a valid indication of maternal preferences.

Table I gives the total number of mothers who were told at different times; the number who were satisfied with the time at which they were told and whether or not they had other criticisms; the number who were dissatisfied, and of these the number who still expressed strong resentment about the time when they were told. The other criticisms made by mothers are set out in Table II. Three mothers had no clear recollection about the time and way they were told.

TABLE I.—*Reactions of Mothers to the Time at Which They Were Told That Their Child Was a Mongol*

When Mother was Told	Total		Satisfied with Time			Dissatisfied with Time		
	No.	%	Total No.	Total %	Other Criticisms	Total No.	Total %	Mother Very Resentful
Before 10 days ..	16	22·5	13	81·3	2*	3	18·7	1
10 days–1 month	2	2·8	1	50·0	–	1	50·0	–
1–6 months ..	20	28·2	12 (2†)	60·0	6	8	40·0	1
6–12 months ..	13	18·3	7	53·8	1	6	46·2	3
1–2 years	7	9·9	3	42·9	–	4	57·1	1
After 2 years ..	9	12·7	2 (2†)	22·2	–	7	77·8	2
?	3	4·2	3					
No information ..	1	1·4						
Total ..	71	100·0	41	57·7	9	29	40·8	8

* Stated that they should have been told even earlier.
† Specified that they did not wish to be told earlier.

TABLE II.—*Other Criticisms Made by Mothers*

	Other Criticisms made by Mothers who were			
	Satisfied with Time	Dissatisfied with Time	Total No.	Total %
1. Told only after repeated questioning ..	2	3	5	7·1
2. Questioned at birth but reassured ..	–	3	3	4·3
3. Referred to hospital, reassured ..	–	3	3	4·3
4. Told on hospital admission for another condition	1	1	2	2·9
5. Told on application for emigration ..	–	1	1	1·4
6. Husband told early, wife told later ..	–	1	1	1·4
7. Given too gloomy a prognosis ("will never walk or talk")	1	3	4	5·7
8. Given too optimistic a prognosis ("may grow out of it")	–	1	1	1·4
9. Did not understand implication of "mogolism"	1	–	1	1·4
10. Not told about associated congenital heart defect	–	1	1	1·4
11. Method of telling abrupt, blunt, or unsympathetic	2	1	3	4·3
Total	7	18	25	35·6

Of the 16 mothers told shortly after birth, three would have preferred to have been told later, when they were more fully recovered from the confinement. One of these still expressed considerable resentment at the shock she had received. Of the 13 mothers who were glad to have been told at once, one spoke of her great distress at the time but thought that it was preferable to get over the initial shock while still in hospital. All other mothers who expressed dissatisfaction at the time they were told wished to have known earlier,

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although one who was not told until her child was over 4 years old made the comment that she might not have had another child if she had realized earlier that her first child was mentally defective. The proportion of mothers expressing satisfaction with the time they were told fell from over 80% of those told shortly after birth to 22% of those told after their child was 2 years old.

The mother's social status made little difference to the time when she was first told that her child was a mongol. Rather more of those in social classes I, II, and III were told before one month after birth, but by one year equal proportions in all social classes had been informed.

Mothers of firstborn infants were less likely to be told early than mothers of later-born infants. When the mother had other normal children one in three had been told before one month and only one in ten had not been told by the child's first birthday. When the mongol was a firstborn one in four of the mothers was told in the first month and one in three not until after the first year. Only one of 12 mothers of firstborn mongols had no criticisms to make about the time or method of telling compared with 32 out of 58 mothers of later-born mongols.

Nearly one-half of the total mothers said that they realized before being told that there was something seriously wrong with the child's development. This was no less common when the mongol was a firstborn child. Five mothers recognized the stigmata of mongolism when they first saw their babies; one suspected that something was wrong because "a lot of doctors" (most probably students) seemed interested in the baby, and three others because of their transfer to a single room or special kindness shown by nursing and medical staff. One mother read her case notes.

After discharge from maternity hospital five mothers experienced considerable difficulties in management and feeding but were given no explanation of the cause; two of these were mothers of firstborn mongols and had attributed the difficulties to their own inexperience. Nine mothers stated that they could have been spared months of uncertainty and unexpressed fears if they had been told earlier. Only three complained that they had been told in an abrupt, blunt, or unsympathetic manner, which makes it unlikely that many of the criticisms voiced stemmed from resentment felt against the individual who first revealed that the child was mentally defective.

To sum up, the mothers who spoke most appreciatively about the way they had been told were those who, having been warned or told soon after birth, were given a full explanation at that time or within the next three months, more especially if thereafter they were encouraged to return to the family doctor or paediatrician with any further queries or problems and were given regular support and advice throughout the early years. The mothers who were still most resentful were those who had suspected that their child was not normal, had sought advice on this account, and had been reassured that there was nothing seriously wrong.

Summary

During an aetiological study of severe mental subnormality in Edinburgh, mothers of mongol children supplied information about when and how they first learnt of their child's defect and their reactions to the time and method of telling. A full explanation given in the early months, coupled with regular support thereafter, appeared to facilitate the mother's acceptance of and adjustment to her child's handicap.

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Medical Memoranda

Haemolytic Anaemia Associated with Ovarian Teratoma

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Ovarian tumours are known to be associated occasionally with haemolytic anaemia, but the association is apparently a rare one, only nine cases being recorded. A further case is reported here.

Case Report

An unmarried woman, aged 48, was admitted to Aberdeen Royal Infirmary on 7 April 1963 with a three-month history of jaundice and increasing dyspnoea on effort. She had never been jaundiced previously, and there was no family history of jaundice.

She was well nourished, pale, and moderately icteric. The liver edge was 2 in. (5 cm.) below the costal margin and the spleen was easily palpable. A tumour was noted in the lower abdomen slightly to the left of the midline, and was found on bimanual examination to be a firm rounded cystic swelling about the size of a grape-fruit. Radiographs of the pelvis showed a dermoid tumour about 4 in. (10 cm.) in diameter that was more than half-filled with fat and contained several teeth.

Investigation showed a severe haemolytic anaemia. Prednisone in a dose of 60 mg. daily was given from 6 to 14 May, but the haemolysis was unaffected and on 14 May six units of packed cells were transfused.

On 23 May Dr. J. F. B. Wyper removed a large left-sided ovarian tumour. The right ovary appeared perfectly healthy, as did the uterus apart from the presence of a small fibroid. She made an excellent post-operative recovery. The haemoglobin level was well-maintained and three weeks after operation there was no evidence of excessive haemolysis. This was confirmed at repeated reviews during the following 12 months.

Her married sister, aged 59, was examined. She showed no evidence of excessive haemolysis, and the appearance and osmotic fragility of the red cells were normal.

Laboratory Investigations.—Haematological and biochemical data are presented in the Table. The osmotic fragility of the red cells on three occasions is shown in the Fig. The patient's blood was Group A Rh-positive. The direct Coombs test in serial dilutions was negative. No autoagglutinins were detected at 4° C., room temperature, or 37° C. No alpha-, beta-, or auto-haemolysins were detected at room temperature or at 37° C. The blood Wassermann reaction was negative. Examination of the sternal marrow showed very marked normoblastic and macronormoblastic hyperplasia. The