Congenital Defects: Mothers' Reactions to First Information

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Since it is natural for a mother to expect her baby to be perfect she is bound to be shocked and upset when she is told that he is in some way abnormal. Such information will inevitably be painful for her to receive, and the task of telling her must always be a difficult and unpleasant one.

The following account is based on a study concerning congenital abnormalities which included an attempt to find out from mothers how, when, and from whom they first learned about their babies' defects, and to get their opinions. Very little seems to have been written on this topic except in the case of mongolism—for example, Drillien and Wilkinson (1964)—and spina bifida (Hare *et al.*, 1966).

Material

A total of 694 mothers were interviewed, some in hospital but the majority (over 600) in their own homes. All had had a baby with one or more of the defects listed in the Table. Some of the mothers had had more than one baby with a congenital defect.

Defects Found in 694 Cases

Type of Abnormality	Mothers Interviewed			
	No.		%	
Anencephaly	96		13·8	
Spina bifida	194		28·0	
Mongolism	90		13·0	
Cleft lip and/or palate	54		7·8	
Congenital heart disease	199		28·7	
Intestinal obstructions	42	61	6·1	8·8
Exomphalos	9		1·3	
Hirschsprung's disease	10		1·4	

Names and addresses were obtained from the Liverpool Congenital Abnormalities Register (Smithells, 1962). Illegitimate babies were excluded from this study. Most of the babies were born during the four-year period 1960–3. The mothers were interviewed during 1966 and 1967.

Method

The addresses obtained from the registry records were first checked by health visitors and corrected if necessary. Some families could not be traced or had left the area. Mothers still resident in the area were first approached by letter and invited to help in the study. If no reply was received a second letter was sent. The great majority agreed (26 refused) and home visits were then arranged. Some mothers of spina bifida babies were interviewed at the time of a hospital outpatient visit.

The interviews, whether in the home or in hospital, were informal and semi-structured. Mothers were encouraged to give their own opinions. Each mother was asked how she was told about the defect, when she was told, and by whom. If the baby had been stillborn these questions were not asked until it was clear that she knew about the abnormality. If she knew only that her baby had been stillborn, and was obviously unaware that there had been any malformation, the interview was modified to relate to stillbirth and not to congenital defect.

Results

Anencephaly

This abnormality is considered first because the acuteness of the suffering of the mother of an anencephalic baby does not seem to be generally realized.

Out of the 96 mothers interviewed who had each given birth to an anencephalic baby (in six instances, two anencephalic babies) over a third had some criticism to make. Most mothers were told by a doctor or a nurse immediately after the birth that the baby was stillborn and in some way deformed. A mother not specifically told the nature of the malformation was liable to conjure up ideas of a weird and shapeless monster. One mother who had never dared to voice her fears retained such an impression years later. A few mothers of anencephalic babies complained that their questions were ignored. When they were not given answers to their questions their anxiety was increased. "There was silence and hedging whenever I asked a question." Another mother complained that when she asked a question "they went out and left me." Some mothers said that they were too fearful to ask any questions after overhearing remarks made by medical students and nurses—for example, "It's more like an animal than a human being"; "There's no head"; "Oh, look at its eyes." One mother became very alarmed about her baby because all the nurses "were huddled in one corner."

A few mothers did not know for months or even years after the birth that the baby had been deformed. One said that she only learned when she was being examined during her next pregnancy. The doctor said, "This one's got a good nut, anyway," and then had to explain his remark. These mothers said that they would have preferred to know at the time of the birth that the baby was abnormal. The only exception was a mother who did not think she would have had the courage to have another child if she had known.

It was evident that many of the mothers would have appreciated more attention paid to them, and more opportunity to ask questions and to have their unvoiced fears allayed. One mother spoke with particular appreciation of the fact that the nurses gave her extra attention as though they realized that she needed it more than the mothers with babies.

It is common practice after the birth of a stillborn baby for mothers to be put on their own or in a ward where there are no babies. Mothers found this a help. Only one mother who was put on her own said she would have preferred to have the company of the others.

The mother's sense of loss and grief seemed to be more acute than that of the mother whose malformed baby survived, especially if the infant was first-born. In most cases, however, the mother of the anencephalic baby recovered from the tragedy sooner than did the mother of a surviving baby with a severe congenital defect. Having another baby seemed to be the best cure for the heartache of the mother who had had an anencephalic baby.

Spina Bifida

The majority of the 194 mothers of spina bifida babies interviewed had been delivered in hospital, and a doctor had in

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most instances told them about the defect, usually within a short time of the baby's birth. About two-thirds of the mothers seen were satisfied by the way they were told about the defect, and by the fact that an explanation was given so soon after the baby's birth.

Mothers disliked being given an unnecessarily gloomy picture when they were first informed—for example, the mother who was told that her baby would be " mental and paralysed " even if an operation proved possible. They also disliked having the seriousness of the condition minimized, learning the truth later—for example, the mother who was told by the midwife that the baby had " just a small pimple on her back, but that it was nothing for her to worry about." A few mothers complained that they were merely told that the baby had spina bifida, as though they understood what the term meant.

Mothers remarked that it had meant a great deal to them, when the baby had been sent to another hospital for operation, if the nursing staff kept them informed of the baby's progress. Some mothers were unfortunately too timid to ask for progress reports or too frightened by the thought that the baby might have died.

Mongolism (Down's Syndrome)

After interviewing 90 mothers of mongol babies it was evident that the substantial majority preferred to be told the diagnosis as early as possible. In many instances the mother strongly suspected it, but did not want to ask, as she dreaded having her suspicions confirmed. Then, as time elapsed, her fears increased or her hopes mounted, depending on how alarmed she was by the baby's appearance. When these mothers finally learnt the truth they felt the shock was greater than if they had been told earlier. One mother spoke of her " terrible three months," hoping that someone would tell her that her baby was not a mongol.

Mothers felt strongly that if they did ask about the baby they wanted the truth. An early denial made it harder for the mother to accept the truth later.

With mongolism, as with every type of defect studied, there were found to be exceptions to the general opinion expressed. Some mothers who had not learned within days or weeks that their baby was a mongol said that they were quite satisfied to be told within a few months. One remarked that she thought a mother should learn to love her baby before being told he was a mongol. Some admitted that they only gradually accepted what they had been told as they noted the difference in progress between the mongol and other children.

Mothers whose babies had also a physical defect—for example, congenital heart disease—and who were only told initially about the physical defect, said that they would have preferred to know about both defects at the same time.

When mothers were not told early about their baby being a mongol—that is, within days or weeks—there was a risk that they would find out accidentally. One mother who took her baby into hospital because he had a chest infection was horrified when the sister remarked to her that " these little mongols are all the same," implying how susceptible they were to infection.

Cleft Lip and/or Cleft Palate

Fifty-four mothers of babies with cleft lip and/or palate were interviewed. Though most mothers understood the term " hare lip," they were nevertheless invariably shocked when the baby was shown to them. Even when they had known other children with cleft lips, they had not seen the condition before operation unless they had previously had an affected child. In isolated cases a mother had no idea what the term " hare lip " meant. One imagined that the baby had a " hairy mole " on the lip, and was stunned when she saw the baby. Most mothers were greatly helped by seeing photographs of how the lip would look after operation.

Congenital Heart Disease

Of the 199 mothers interviewed, three-quarters were satisfied with the way in which they were told about the baby's heart condition. Some would have preferred to know earlier about the defect. Some of them appreciated that the condition could not always be diagnosed at birth.

Mothers were normally told about the heart defect by a doctor. Some who suspected that something was wrong with the baby felt that they were kept in the dark, and all felt more anxious because they could not get anyone to listen to them. When they asked what was the matter with the baby they received evasive replies. One mother said that her baby had " looked black " to her, but whenever she asked the nurse about her infant she was told, " He's resting." This mother did not learn of his heart condition until after his death a few days later.

At times, on discharge from hospital, a mother was told to bring her baby back for review, but no reason was given. When she was told weeks or months later that the baby had a heart murmur she invariably said she would have preferred to know why she was bringing the baby back to the hospital clinic.

Many mothers learned from their general practitioners or from welfare clinic doctors that their babies had heart defects. When clinic doctors were the informants the babies were usually only a few weeks old. The mothers in these instances thought they should have been told by the maternity hospital because " the doctors must have known." Diagnosis by general practitioners was usually made when the babies were a few months old, often at the time of some respiratory infection. On these occasions many mothers failed to recognize the congenital nature of the lesion, and were less inclined to blame maternity hospital staff.

Most doctors who referred a child to a specialist because of some heart defect told the mother what they suspected was the matter with her child. A few mothers claimed that the referral was made without any reason being given. In two instances the mother spoke of the terrible shock she got when she discovered while in the hospital waiting-room that her child was to see a heart specialist.

Intestinal Obstruction, Exomphalos, and Hirschsprung's Disease

Criticisms raised by some mothers were similar to those already mentioned—for example, lack of information. One mother said that she was told, " You are not supposed to ask questions." Some mothers had great difficulty in persuading the nursing staff to let them see their babies before they were transferred for operation. One mother whose baby had died after operation remarked, " I think I could have got over it better if I'd seen her."

Discussion

Because mothers differ so much one from another, and because congenital abnormalities are so varied in type and severity, a diversity of opinion is to be expected among 694 mothers regarding how and when they were told about their babies' defects.

The views most commonly expressed concerned: (*a*) a sympathetic and undertanding approach by the medical and nursing staff, particularly at the time the baby is born; (*b*) the importance of simple language ; (*c*) the mother's need to ask questions ; and (*d*) the desire for truth, avoiding unjustifiable pessimism and unrealistic optimism.

Mothers attached great importance to the approach and general attitude of the medical and nursing staff who told them about their babies, particularly if they learned soon after the baby's birth. Very often she could not remember exactly what had been said, but she could always recall whether the informant had an understanding approach and seemed aware of her suffering. Mothers who were hurt by seeming lack of sympathy towards them tended to attribute the abruptness to lack of feeling of the informant rather than to the likely cause—that is, the difficulty of imparting such information. Most mothers were impressed by the kindness and sympathy extended to them by medical and nursing staff. Small acts of kindness were clearly remembered years after the event.

Mothers liked to be told what was wrong with their babies in simple language. One mother remarked, " No one told us what was wrong with the baby in words we could understand." Long technical explanations were not welcome. One mother said, " He told us so much we'd forgotten by the end what he'd said at the beginning."

The need to ask questions was frequently mentioned. Many mothers who wanted to ask questions did not do so because they were timid, or inarticulate, or because " everyone seemed so busy." These mothers would have asked questions if encouraged to do so. Other mothers claimed that they asked questions but were ignored. Yet others wanted to be told about the baby but feared to have their suspicions confirmed.

Mothers liked to be told the truth about their babies. They became increasingly anxious if merely told not to worry. Mothers who felt the truth was being hidden from them worried more. " The suspense was worse than knowing " ; " You worry less when you know."

It is appreciated that the mothers' recollection of what they were told at the time their babies were born was not necessarily reliable, and that the personality of each mother determined to some extent her satisfaction or dissatisfaction with the way in which she was treated at the time of her baby's birth. Nevertheless, it is essential to ensure so far as is possible that she understands what the doctor is saying.

It is evident that the initial counselling of the mothers of malformed infants makes a deep and lasting impression.

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REFERENCES

Drillien, C. M., and Wilkinson, E. M. (1964). *Brit. med. J.*, **2**, 1306.
Hare, E. H., Laurence, K. M., Payne, H., and Rawnsley K. (1966). *Brit. med. J.*, **2**, 757.
Smithells, R. W. (1962). *Develop. Med. Child. Neurol.*, **4**, 320.

NEW APPLIANCES

Aid to Urethrography and Cystography

Dr. J. D. **Jeffries**, North Middlesex Hospital, London N.18, writes: The apparatus described below weighs 25 g. and adheres to the penis by suction. It allows the radiologist to manœuvre the penis into whatever position is required, and has been found of great assistance in urethrography. It can also be used to fill the bladder for male cystography, obviating the need for catheterization and so reducing the risk of infection. As it causes only minimal discomfort local anaesthesia is not usually required. The radiation hazard to the radiologist is eliminated, as media can be inserted into the urethra from a distance via a connecting tube while screening.

Use.—An appropriate size face-plate is chosen and screwed on to the body (see Figs. 1 and 2). The projecting nozzle is then inserted into the urinary meatus and advanced until there is total circumferential contact between the aperture in the face-plate and the glans penis (Fig. 3). Suction is then applied which draws the glans penis towards the vacuum chamber so that the apparatus adheres to the glans. Suction sufficient to hold the apparatus in place is usually 0.5 kg./sq. cm. A pressure gauge is useful to tell if there is a leak in the circuit. The contrast medium is then injected down the central channel into the urethra: 12.5% Hypaque (sodium diatrizoate) for cystography, Umbradil (diodone) for urethrography.

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Fig.1

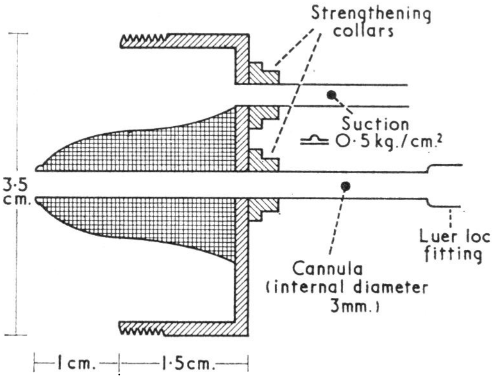

Fig.2

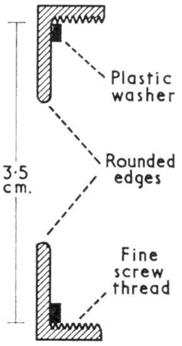

Fig.3

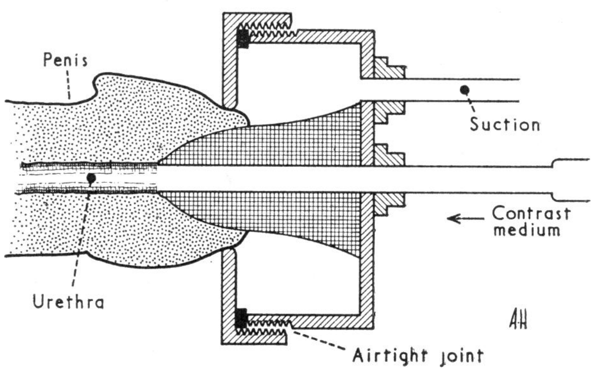

Fig. 1.—Body. Coronal section of cylinder. **Fig. 2.**—Face-plate. A set of four circular face-plates with central apertures of 1, 1.5, 2, and 2.5 cm. were used. **Fig. 3.**—Apparatus assembled and in use. The apparatus is made of Perspex except for the central cannula, which is of metal.