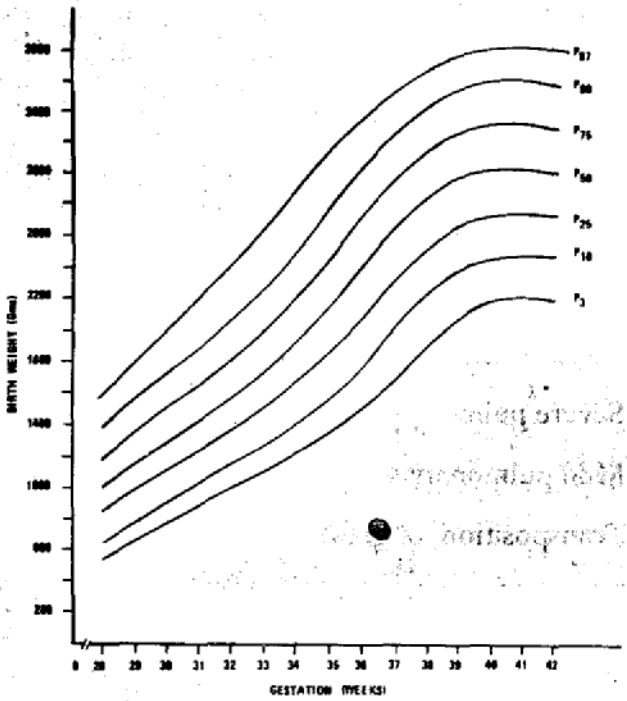

Fig .Percentile weight curves for both sexes.

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Mothers' Perception of Congenital Heart Disease

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Understanding of the nature of the congenital heart disease (CHD) by parents is important in the management of children with CHD. Unfounded beliefs and wrong perceptions hinder proper treatment and induce undue anxiety on part of the parents(1-3). Usually parents' understanding of the nature of the heart disease does not correlate well with the underlying anatomic or pathophysiologic defect(2,4). We wanted to enumerate the characteristics of the parents who lacked proper knowledge about their child's illness. This would enable the physicians to identify such parents readily and educate them properly about the child's problem. Enabling the parents to gain right perspective of the illness and its long term prognosis is likely to result in their better participation in the management of the child.

Material and Methods

The study population was mothers of 101 consecutive children with CHD, attending the Pediatric Cardiology Clinic of Nehru Hospital, PGIMER, Chandigarh. A definite diagnosis of CHD and its severity had already been established in the sample population on the basis of clinical examination, electrocardiography and echocardiography. There were 66 boys and 35 girls with age ranging from 1 to 3 years. A pretested questionnaire was administered to the mothers by one of us (RK) who was blinded to the diagnosis. This questionnaire included social, economic, demo-

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graphic and biologic characteristics. The mother's response about the illness of child was recorded verbatim and her perception of the child's cardiac defect was compared with the actual diagnosis. Criteria were developed to label the response correct or incorrect based on the degree of understanding demonstrated by the mother's answer. A response was considered incorrect if it was of a non-specific nature (for example: 'heart disease', or 'hole in the heart') without knowing about prognosis or future possible management. Severity of the cardiac illness was defined both on the basis of anatomic defect and its physiological consequences as a result of investigations (*e.g.*, large left to right shunt with failure or complex congenital anomaly–severe; small ventricular septal defect–mild). Bivariate contingency table analysis was performed using Chi square test to assess the statistical significance of the difference between variables and mothers' understanding of child's medical condition.

Results

The etiologic diagnosis of various types of CHD are provided in *Table I*. The factors studied and the number of correct responses are listed in *Table II*. A correct description of the understanding of the illness was given by 49% of mothers. The proportion of mothers providing correct description increased with increase in literacy and socioeconomic status ($p=0.02$). A negative correlation was found with increase in age parity ($p<0.05$).

There was no correlation between correct maternal response and age at which the diagnosis was made, number of doctors consulted and the number of hospital visits. The number in which the diagnosis was suspected antenatally because of a history of sibling having heart disease was 3 and one of the mothers from this group responded correctly. The severity of cardiac illness reduced the number of correct maternal responses (55.8% in mild vs. 44% in severe); however, this was statistically not significant. The nature of underlying heart disease did not have any bearing on maternal understanding. The mothers of boys with CHD gave a correct description less frequently as compared to those with girls (41.8% vs. 62.9%, $p< 0.05$)

TABLE I–*Underlying Cardiac Illness in the Children of Study Population*

Small ventricular septal defect	31
Large ventricular septal defect with CHF	25
Tetralogy of Fallot	26
Atrial septal defect	3
Bicuspid aortic valve mild aortic stenosis	2
Patent ductus arteriosus	5
Severe pulmonary stenosis	2
Mild pulmonary stenosis	1
Transposition of great vessels	5
Tricuspid atresia	1
Total	101

Discussion

Fifty one per cent mothers did not have proper understanding of the illness in their offspring which indicated poor doctor patient communication. The possible reasons for this communication gap could be (*a*) less time spent per patient in explaining the illness as a result of large number of patients attending out patients' department and (*b*) inability of the physician to find the

TABLE II— *Relation of Socioeconomic and Demographic Variables and Mothers' Understanding of Congenital Heart Disease in Child*

Variable	Number of respondents	Correct response	
	(n=101)	n	(%)
Maternal education*			
Illiterate	26	9	(34.6)
Primary	18	8	(44.4)
Secondary	47	27	(57.4)
Graduate and above	10	6	(60.0)
Socioeconomic status*			
Poor	34	12	(35.3)
Middle income	57	32	(56.1)
High income	10	6	(60.0)
Parity**			
1	32	15	(46.9)
2	32	21	(63.6)
≥3	37	13	(37.8)
Maternal age (years)**			
<20	16	9	(56.2)
20-24	42	23	(54.8)
>24	43	18	(42.9)
Number of doctors visited			
<5	36	18	(50.0)
6-10	56	27	(49.1)
>10	9	5	(55.5)
Number of hospitals visited			
<5	60	23	(38.3)
6-10	31	11	(34.3)
>10	10	2	(20.0)
Age at which diagnosis made (years)			
<1	54	31	(58.5)
1-2	32	13	(40.6)
>2	15	6	(40.0)
Severity of child's illness			
Mild	38	21	(55.8)
Moderate	37	16	(43.2)
Severe	26	12	(44.0)

* $p = 0.02$, ** $p < 0.05$,
statistically insignificant values in others

understandable vernacular equivalents to the medical facts. Involvement of nurses and social workers can prove useful in improving the communication.

Of the variables studied, higher maternal literacy and higher socioeconomic status showed positive correlation with the maternal understanding of child's cardiac illness. Increase in number of babies and higher maternal age showed a negative correlation with maternal understanding. Such a correlation has been shown earlier in Western studies(2-4). With the low literacy rate in India, such a study is relevant.

With many recent advances in medical technology and various complexities involved in diagnostic and management procedures, the time spent and the proper communication between a physician and patient (in this case the patients' parents) has become difficult. This is a potential source of stress and anxiety for parents. Such a stress has been found to lead to inadvertent non-compliance of physician's instructions and deformed perceptions regarding severity of the disease(3). In the present study, we noticed that mothers with children having milder disease fared better as compared to mothers with infants having severer disease (55.3% vs 44%). This is probably because stress of severer disease interfered with proper perception- a denial phenomenon. Several authors have observed this fact(5,6). The severer the disease the more stressed the parents are and more attention they need from health personnel in the form of health education.

More correct responses were obtained from mothers of female children; this could be because of social reasons– mothers being more worried about female offspring and her future.

The number of doctors consulted or

number of hospital visits did not affect the number of correct responses. This was probably result of busy clinics and less time spent per patient on every subsequent visit. Moreover on subsequent visits, once the diagnosis has been established the doctor as well the parent is concerned about the concurrent illness.

Although medical personnel are often aware that particular attention is given to the parents who are at socioeconomic disadvantage in terms of better communication, other groups which require extra help are mothers with advanced age and those with more children. A cross check on mothers' understanding is recommended so that gaps in knowledge can be mended.

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Spontaneous Regression of Bilateral Retrobulbar Masses in a Newborn —? Neuroblastoma

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Retrobulbar orbital lesions are uncommon in the newborn. Their etiology includes hemorrhages, vascular malformations, dermoids, teratomata, orbital encephaloceles, tuberculous granulomas, abscesses, and tumors like neuroblastoma, neurofibroma and rhabdomyosarcoma(1). Bilateral lesions, however, are extremely rare(1). A neonate with bilateral retrobulbar masses and a probable diagnosis of neuroblastoma is reported.

Case Report

A male child weighing 3.1 kg, born at full term of an uneventful vaginal delivery, was noted to have bilateral proptosis at birth. Examination revealed extensive subconjunctival hemorrhages, chemosis, semidilated sluggish pupils and incomplete lid closure bilaterally. Ocular fundoscopy and systemic examination were normal. The clinical impression was bilateral

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