

## Parental Knowledge and Views of Pediatric Congenital Heart Disease

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### Abstract

**Background:** Parental knowledge of their child's heart disease, while often overlooked, contributes to compliance and reduces anxiety. Prior studies have shown that 36% of parental diagnostic descriptions are incorrect.

**Objectives:** To assess parental knowledge and attitudes among outpatients at a hospital pediatric cardiology clinic.

**Methods:** Seventy-four families completed a questionnaire in which they described their child's condition and stated their attitude towards dental hygiene and future prenatal diagnosis.

**Results:** Eighteen percent of the parents failed to describe their child's malformation correctly. We found that parental understanding of the heart defect correlated with parental education. Future prenatal diagnosis was considered by 88% of families, and termination of pregnancy by 40%. Only 40% of children were aware of their heart problem. Children of parents who were ignorant about the condition tended to lack knowledge themselves. An additional finding was that 68% of Jewish families turn to non-medical personnel for medical advice – an interesting finding not hitherto addressed.

**Conclusions:** Ignorance of their child's problem did not correlate with its severity or complexity but rather with parental background: the less educated the parent, the more likely was the problem perceived incorrectly.

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Studies of children with congenital heart disease performed in the United States have shown that parental knowledge about their child's disease may be incorrect in as many as 36% of cases [1]. Understanding CHD has been shown to both promote parental compliance [2] and reduce anxiety [3] in children and their parents. The lack of parental knowledge carries over to the patients' perception of their own medical problem, enhances their anxiety and reflects on their body image and healthcare attitude [4–6]. Comprehending the true nature of the heart disease is not an easy task for many family physicians and pediatricians, and we hypothesized that it is a difficult task for parents who lack a medical background.

The primary purpose of this study was to assess, for the first time in Israel, parental knowledge of their children's heart disease, as well as to identify socioeconomic variants relating to the knowledge. Also obtained were information-related attitudes towards future pregnancies. Patients older than 4 years of age were asked why he/she came to the clinic, and, if they knew they had a heart problem what the nature of the trouble was. We evaluated the families' knowledge of the importance of dental hygiene and inquired whether they are aware of the need for prophylactic antibiotics when there were an indication. Finally, we wished to assess the prevalence of extra-medical consultants. In the past few years there appears to be a growing tendency among Israeli patients to seek advice from non-medical authorities such as rabbis, people renowned for their knowledge of *Kabalah* (Jewish mysticism), or "blessed" elders of the community. The prevalence of this trend has not yet been studied.

### Subjects and Methods

The study group comprised 74 children aged 2 weeks to 19 years (mean age  $49.8 \pm 7.27$  months) chosen randomly from those who visited the pediatric cardiology outpatient clinic at Hadassah University Hospital between September 1996 and November 1997. The patients were under the care of one or more of the pediatric cardiology staff. The patient's cardiac problem was explained to the parents following the diagnosis and at the subsequent follow-up visits. Many times the explanation was aided by drawings. No attempt was made to enhance education in the study group with regard to their child's heart condition. Following their routine visit, each family was requested to complete a short questionnaire. An effort was made to interview the families in the parents' native tongue (Hebrew or Arabic). The interview was conducted by medical personnel who were not part of the cardiology clinic's permanent staff. In addition to sociodemographic information, parents were asked to answer the question "what is your child's heart problem?" and to give an assessment of the problem's severity and the child's perceived prognosis. Parental description of their child's problem was considered correct if the anatomy or physiology of the defect was appropriately described, regardless of whether the appropriate medical terminology was used. A response was considered incorrect if it was of a non-specific nature (e.g., "heart murmur") or included wrong

CHD = congenital heart disease

**Table 1.** Distribution of cases by morphologic severity of cardiac defect

Grade	Description	Patients	
		No.	%
1	Simple septal defects	15	20
2	Mild valvular or great vessel lesions	15	20
3	Complicated septal/ valvular lesions	22	30
4	Looping abnormalities, major septation and conotruncal abnormalities, hypoplasias and atresias	16	22
5	Same as 4, complicated by repeated surgical procedures or complications	6	8

anatomic or physiologic descriptions. The parents were also asked whether they would undergo a prenatal echocardiogram in future pregnancies and whether they would consider terminating a pregnancy should a heart defect be found. Another part of the questionnaire related to parental knowledge on the necessity of dental hygiene and the need for prophylactic antibiotics before dental procedures. The socioeconomic data obtained were:

- Maternal and paternal age
- Nationality
- Religious self-definition
- Education level (years schooling)
- Occupation of mother and father
- Prenatal/postnatal diagnosis
- Presence/absence of non-cardiac defects

The parents were assured of the anonymity of their answers. Only two families refused to participate. The patients' medical records and echocardiograms were then reviewed and the distribution of cases by morphologic severity of cardiac disease defined [Table 1]. Of the 74 families interviewed, 50 were Jewish (67%) and 24 were non-Jews (33%) (23 Moslems and one Christian) and 62 (84%) defined themselves as religious and 12 as non-religious. Consanguinity was found in 13 families (18%), of which 9 were first-degree cousins (8 Moslem families, one Jewish family). With regard to parental occupation, 50% of the mothers were homemakers and 23% were professionals; and 69% of the fathers were laborers, 20.5% were professionals, 7.5% were Yeshiva scholars, and 3% were unemployed.

### Statistical analysis

Descriptive statistics, one-way analysis of variance and Kruskal-Wallis one-way analysis of variance on ranks were applied as appropriate and analyzed using Jandel Scientific software (San Rafael, CA, USA). Pair-wise multiple comparison procedures were performed using the Student-Newman-Keuls method in order to compare correct and incorrect answers. A *P* value of 0.05 or less was considered significant.

### Results

Overall, 13 of the parents' diagnostic descriptions (18%) were classified as incorrect and 61 (82%) as correct. Parental age, occupation, and the number of children per family were not

**Table 2.** Comparison between parents with and without correct knowledge of their child's cardiac diagnosis

	Entire group (mean, range)	Correct knowledge (mean ± SD)	Incorrect knowledge (mean ± SD)	<i>P</i>
Age (yr)				
Father	36.1, 23–57	36.2±8.4	35.5±7.2	NS
Mother	32.8, 16–54	32.9±8.0	31.6±7.2	NS
Years schooling				
Father	12.8, 6–23	13.3±1.3	10.5±1.8	<0.05
Mother	12.1, 0–19	12.6±2.4	9.8±3.5	<0.05
No. of children	3.76, 1–13	3.77±2.47	3.69±2.01	NS
Cardiac lesion complexity	2.8, 1–5	2.7±1.0	3±1.0	NS

correlated to description accuracy, nor was the severity or complexity of the defect, or past or future procedures. The correct answers were significantly correlated to paternal (*P*<0.05) and maternal (*P*<0.05) education [Table 2].

### Future prenatal diagnosis

Future prenatal diagnosis would be considered by 88% of families and abortion by 40%. The wish for future prenatal diagnosis was not correlated to religious self-definition, even though consideration of possible abortion clearly was (*P*=0.0006). Refusal to undergo prenatal echocardiography was closely related to religious attitudes (“we will not consider abortion anyway”), although some families stating refusal to consider termination of pregnancy indicated that they would like to undergo prenatal diagnosis in order “to know and be prepared.” One family refused to answer, the father stating that “one child is enough.” In several cases, the interviewing staff felt that there was a discrepancy between parental attitudes – mothers tended to favor prenatal diagnosis and to consider possible abortion more than fathers did; however, no overt disagreement was registered. In one case, the father simply declared “it is for the man to decide.” The nature of the interview did not permit quantification of such discrepancies. Reasons for refusal to consider abortion were religious.

### Parental satisfaction

Satisfaction with the information given by the doctors was expressed by 95% of families, and 97% stated that they trust the physicians.

### Extra-medical consultants

With regard to our question whether families made medical decisions according to medical advice only or whether they resorted to other sources, 68% of Jewish families stated that they seek advice from non-medical personnel, while all the Moslem families denied seeking advice outside medical circles. In addition, 75% of Jewish parents used amulets and blessings or placed the Book of Psalms in the crib. Some families believed that the amulet determines a substantial part of the child's well being, while others said they used them “to be on the safe side.”

Among Moslem families, the only rite described was the placing of a Koran in the child's crib.

### Dental hygiene

Awareness of the need for dental care was noted among all families, except for six families (8.5%) whose child would need prophylaxis in accordance with accepted criteria. In two of these six families the child was under 1 year of age.

### Patients' awareness

Only 8 of 20 patients (40%) above 4 years of age were aware of having a heart problem. Three mentally retarded children are excluded from these results. Some of the children could use medical terminology ("I have Fallot") but were unable to elaborate. Several referred to their problem with nicknames (a 5 year old child with a corrected ventricular septal defect giggled, "I have a hole in the ozone layer"). In contrast, a 15 year old with Fallot post-repair refused to acknowledge any existing problem ("I'm completely healthy. This is a routine check-up"). When discussing the problem with the doctor, one ultra-orthodox family sent their 14 year old out of the room, refusing to include the boy in the interview.

## Discussion

About 0.8% of live births are complicated by a cardiovascular malformation. This does not include small preterm infants, many of whom have persistent patent ductus arteriosus. Extracardiac anomalies occur in about 25% of infants with significant cardiac disease [7]. Since modern medicine has the ability to correct many previously lethal conditions, the population of survivors grows with each passing year. Despite these improvements, there is an enlarging population of children who suffer from chronic problems. In addition to the medical aspects of their plight, these youngsters also have problems of self-image, anxiety and insecurity. The parents may react to a child's problem in different ways – some families are over-protective, while some abuse or neglect their sick child.

In our study, only 18% of the parents could not describe their child's ailment. This ignorance did not correlate with the severity or complexity of the problem, but rather with the parental background: the less educated the parents, the more likely they were not to perceive the problem correctly.

Research on this subject in the United States demonstrated that parental knowledge was incorrect in 36% of cases [1]. It was also found that an adequate comprehension of CHD serves to both promote parental compliance and reduce anxiety. The lack of parental knowledge seems to extend to the patients' perception of their own medical problem, and affects their body image and healthcare attitude [2,3,6]. In a recent study, follow-up of patients with congenital heart disease who had been assessed 25 years previously revealed that these patients had evidence of excess psychological stress. The authors speculate that these patients were exposed to

psychological environmental stresses that may well have been colored by parental perception [8].

### Future prenatal diagnosis

It has been shown that negative fetal echocardiography reduces parental anxiety [9]. The concept of future prenatal diagnosis was welcome among all groups in our study, regardless of nationality, religion or the complexity of the child's defect. Parents who stated that they would not consider termination of pregnancy still wished to undergo prenatal echocardiography in order to reassure themselves of the fetus's health.

### Patient awareness

Only 40% of children of appropriate age had correct knowledge of their heart problem. However, most children who were unaware belonged to the group whose parents did not understand the cardiac problem, which explains the child's ignorance. Six of the eight children who were unaware of their problem belonged to that group (75%), while 12 of 17 children whose parents did understand the problem were aware of their condition (70%). This finding reflects the same trend observed in a Canadian study of adult patients with CHD, in which only 54% of the patients knew their diagnosis [10].

### Dental hygiene

Previous studies have found that low compliance and lack of knowledge seriously increase the risk of endocarditis [11,12]. In our study only a small minority of the families was unaware of the need for prophylaxis. However, we did not check whether the families actually complied with the instructions and whether this compliance could be related to their knowledge and understanding.

### Non-medical consultants

We have no previous data to compare the prevalence of non-medical consultations, nor did we examine the influence on decision-making. Our study did not differentiate between those who seek blessings or use amulets and those who actually base their medical decisions upon the advice of non-medical personnel. We assume that the second group would be smaller than the first. However, we did encounter decisions taken contrary to medical advice on the grounds of a different prognosis predicted by non-medical personnel. Nonetheless, many of our patients felt the need to resort to non-medical help, irrespective of the fact that 95% expressed themselves content with the information given and that they "trust" the physician.

### Limitations

Our study population is unique and cannot be compared to the studies done in United States. One cannot even presume that studies done in other parts of Israel will yield similar results. Our population reflects patients seen in a tertiary referral center located in an area in which 62% are religious (in contrast to some 30% in the general Israeli population). Religious self-

definition reflects on decision-making procedures and on attitudes towards diagnosis in future pregnancies.

## Conclusions

Of the 74 families who participated in our study 18% failed to describe their child's malformation correctly. Only 40% of children of appropriate age had correct knowledge of their heart problem. We found parental understanding of the heart defect to correlate with parental education. Future prenatal diagnosis would be considered by 88% of families and abortion by 40%. A thought-provoking finding that has not been addressed so far was that 68% of Jewish families turn to non-medical personnel for medical advice.

Increased efforts to improve knowledge and compliance should be targeted at families with a low level of comprehension. Strategies to improve parental understanding have been suggested in a previous study by Kupst et al. [13]. There may also be a need to see those patients more frequently in order to assure that the child receives proper medical care. Further investigations are needed to establish better ways of explaining the situation to families of a lower educational level. Similar studies in different medical centers in Israel will show whether the trends shown here reflect the wider population.

## References

1. Kaden GG, Mc Carter RJ, Johnson SF, Ferencz C. Physician-patient communications; understanding congenital heart disease. *Am J Dis Child* 1985;139(10).

2. Offord DR, Cross LA, Andrews EJ, Aponte JF. Perceived and actual severity of congenital heart disease and effect on family life. *Psychosomatics* 1972; 13:390-6.
3. Bruins CK, Teuns T. Cardiac neurosis in childhood. III. The effect of heart disease on the child and family. *Proc Assoc Eur Pediatr Cardiol* 1967;3:17-19.
4. Doucet SB. The young adult's perception of the effect of congenital heart disease on his life style. *Nurs Pap* 1981;13(3):3-16.
5. Gupta S, Giuffre R.M, Crawford S, Waters J. Covert fears, anxiety and depression in congenital heart disease. *Cardiol Young* 1988;8(4):491-9.
6. Ferencz C, Wiegman FL Jr, Dunning RE. Medical knowledge of young persons with heart disease. *J Sch Health* 1980; 50(3):133-6.
7. Friedman WF. Congenital heart disease in infancy and childhood. In: Braunwald E, ed. *Braunwald Heart Disease*. Philadelphia: W.B.Saunders, 1997:877-962.
8. Brandhagen DJ, Feldt RH, Williams DE. Long-term psychological implications of congenital heart disease: a 25-year follow-up. *Mayo Clin Proc* 1991;66(5):474-9.
9. Bjorkhem GJ, Jorgensen C, Hanseus K. Parental reactions to fetal echocardiography. *J Matern Fetal Med* 1997;6(2):87-92.
10. Kantoch MJ, Collins-Nakai RL, Medwid S, Ungstad E, Taylor DA. Adult patients' knowledge about their congenital heart disease. *Can J Cardiol* 1997;13(7):641-5.
11. Saunders CPR, Roberts GJ. Dental attitudes, knowledge and health practices of parents with congenital heart disease. *Arch Dis Child* 1997;76(6):539-40.
12. Cetta FW, Warnes C.A. Adults with congenital disease: patient knowledge of endocarditis prophylaxis. *Mayo Clin Proc* 1995;70(1):50-4.
13. Kupst MJB, Westman S, Schulman JL, Paul MH. Helping parents cope with the diagnosis of congenital heart defect: an experimental study. *Pediatrics* 1977;59(2):266-72.

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