

Psychological Factors in Congenital Heart Disease in Children

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Studies of the psychological aspects of congenital heart disease in children offer some useful insights but are selective in focus and sometimes contradictory in their conclusions. A review of the literature yields these major findings: (1) Many children with congenital heart disease suffer from some degree of diminished self-esteem that does not necessarily correlate with the severity of the handicap. (2) The child's emotional adjustment is, to some extent, a function of the degree of maternal anxiety. (3) Maternal anxiety is primarily a function of the presence of heart disease rather than its severity. (4) Young children, and their parents as well, may not perceive "routine" cardiac catheterization as a benign procedure. (5) Investigations into the possible relationship between cognitive functioning and congenital heart disease have yielded conflicting results.

There is a deficiency of research probing the symbolic meanings a child may attach to having a "bad heart" and the possible interconnections between these symbolic messages and cognitive functioning. On a practical level, health-care professionals seeking to enhance the emotional security of children with congenital heart defects should restrict the use of a priori reasoning and encourage the child to "tell his own story" about his heart.

Although an estimated 30,000 to 40,000 children are born with congenital heart defects each year in the United States alone, exploration of the psychological and behavioral aspects of this phenomenon has lagged behind the development of ameliorative surgical techniques. Available information does

not warrant a generalization that the presence of congenital heart disease always involves psychological disturbance, but there is evidence that many children with cardiac dysfunction suffer from diminished self-esteem.¹⁻⁵

This paper falls into two parts. With the aid of a MEDLARS search, a range of research studies having to do with the emotional effects of congenital heart disease in children are identified and briefly summarized. Then, taking account of the gaps and contradictions in the literature reviewed, some suggestions are offered for more productive

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exploration of the "inner world" of such children. The larger purpose of the exercise, of course, is to look for ways in which health-care professionals and parents can assist children in "dis-identifying" with their heart disease.

Literature Review

A majority of the studies reviewed used the interview technique. One of the earlier projects, in which 25 mothers of children with congenital heart disease were questioned, yielded certain common themes: mothers tended to focus on their vague apprehension about the newborn child, feelings of maternal guilt but also disappointment and irritation associated with the burden imposed by such a child, anxiety over the child's symptoms and fears of his/her possible death, and attempts to provide the child with a normal life despite some inner constraints on exerting "normal" discipline.⁶ A similar study involving 20 children suggested, in addition, that the mother's perception of the lesion had more influence than its actual severity upon both (1) the mother's view of the impact of the child's abnormality on the family, and (2) the child's view of the effect of his abnormality on the quality of his life.³

In another study, conversations with the families of 100 patients with tetralogy of Fallot, along with 47 comparison families (ascertained by the presence of a child of the same age, sex, and social status), indicated some of the constraints and stresses on family life.⁷ The parents interviewed admitted to appreciable worry and emotional strain, particularly if there were other children. Family recreational activities were restricted and there was a tendency on the mother's part to postpone subsequent pregnancies and a greater willingness to accept sterilization after three or four children. In instances in which corrective surgery had taken place, improvements were noted in the educational progress and social adjustment of the child, with secondary positive effects on the family.

Rozansky and his colleagues reported that denial was found to be the defense most used among parents of 13 cyanotic children who met in six group-therapy sessions led by a psychiatrist.⁸ The parents attempted to counter their anxiety with overprotectiveness. Loss of parental self-esteem and maternal guilt associated with producing an abnormal child were discussed, but the parents tended to avoid expression of deeper feelings about the possibility of their child's death.

The problem of communications between parents of children with congenital heart disease and their physicians was addressed in two papers recently published by the same author. In a 1976 study by Kupst and her co-workers,⁹ 88 parents of children with congenital heart defects agreed to a series of standardized interviews and questionnaires. The participating parents were found to retain much of the information given to them concerning surgery, prognosis, cardiac catheterization, and those matters which tended to involve them directly, eg, activity restrictions and medication instructions. They were deficient (both on a short and long-term basis) in their ability to recall clinical information, such as the name of the defect and its associated hemodynamic consequences. In 1977, Kupst reported the results of an associated experimental study designed to help parents cope with the implications of the diagnosis of congenital heart disease.¹⁰ Intervention strategies, carried out by a multidisciplinary team in a pediatric clinic, involved (1) clarification of medical information, and/or (2) discussion of psychological implications. Parental satisfaction with these services, regardless of degree or type, was generally high, although the long-term benefits to the parents and children are unknown at this time.

Two case reports, one focusing on parents and the other on a child, shed some light on the kinds of psychological effects that the presence of congenital heart disease can produce. Jackson followed on a long-term basis the emotional reactions of the parents of an infant who died, after many months of illness, of congenital heart disease.¹¹ Because of their prolonged grief over this offspring's abnormality, the parents were found to be more able to accept the actual demise of the child. Cline and Rothenberg provided a case report of their work as psychotherapists with a seven-year-old son of parents with serious marital difficulties.¹² The child died, for unclear reasons, one

month following a second surgical intervention for congenital heart disease (ventricular septal defect and pulmonic stenosis). In a play-therapy session preceding the operation, the patient ("Bobby") had described a septal defect "too big" to repair and had concluded that the doll "[would] have to die." The authors hypothesized that "continued parental fighting during the critical postoperative period may have led to Bobby's 'giving up' his futile hope for a more relaxed home atmosphere as well as life itself."

Only two studies among those reviewed attempted to investigate the relationship between the presence of congenital heart disease and a child's self-image. Auer and his colleagues reported the results of their work with 28 children with ventricular septal defect (11 boys and 17 girls, 6 to 11 years of age), half of whom underwent (successful) surgical correction for the defect.¹ Data were obtained from questionnaires, subject interviews, medical records, school reports, and human figure drawings. After surgery, children were characterized as manifesting a significantly greater degree of impairment of intellectual functioning. When asked to depict graphically their concept of their own bodies, they drew "bones" with greater frequency than the group which had not had surgery suggesting a cognizance that surgery involves cutting through the bony thorax. No significant differences were noted with regard to emotional state between the "operated" and the "nonoperated groups," but all the children studied were characterized as seeming "more similar emotionally to children in a psychiatric clinic."

Green and Levitt asked a group of children with congenital heart disease, of varying degrees of physical infirmity and varying incidence of prior surgery, to draw self-portraits as well as pictures of a peer.² Sex-matched healthy controls, retarded children, and emotionally disturbed children were also included in the project. The children with congenital heart disease tended to depict themselves graphically smaller in comparison to the peer portrait than did the normal children.

The emotional effect of cardiac catheterization on children was the focus of a study undertaken by Aisenberg and associates.¹³ Fifty children, 4 to 15 years of age, were subdivided into three age groups and studied before, during, and after cardiac catheterization. Nearly all of the youngest, but less than half of the oldest patients, manifested

negative behavioral and emotional changes after catheterization. Increases in regression, aggression, and emotional lability were observed among the younger children, while heightened levels of general and somatic anxiety were equally distributed among older and younger children. Boys tended to express the above via physical aggression, while girls tended to use verbal aggressive modes.

Barnes and his co-workers, using increases in urinary 17-hydroxycorticosteroid levels as an "objective" measure of stress, studied 11 children undergoing open heart surgery.¹⁴ High levels of this adrenal corticosteroid metabolite were found to be associated with surgery, suture removal, and return visits. Values for overtly more anxious children were no higher than for less anxious children. The authors hypothesized that prepubertal children have insufficient psychological defenses to prevent increased activation of the cortical-hypothalamic-pituitary-adrenal axis in response to the threat of both major surgery and minor procedures—such as suture removal. It is also noteworthy that death fears in the children studied were often correlated with deaths of close relative(s) within the two years prior to surgery.

Linde and his co-workers reported the results of a five-year developmental study of three groups of children: (1) cyanotic children with handicapping congenital heart disease, (2) acyanotic children with handicapping congenital heart disease, and (3) healthy controls.⁵ Each subject was administered a developmental and/or intelligence test appropriate to his age, and these data were supplemented by direct observation of the child's test behavior as well as semi-structured interviews with the mother. Earlier findings indicated that poor adjustment and insecurity in the cardiac child were related more to maternal anxiety and pampering than to the degree of the incapacity.⁴ Although maternal protectiveness (best predicted by maternal anxiety) was highest in the cyanotic group, it seemed more related to the presence than to the severity of the heart disease. Cyanotic children showed a lag in intellectual development, with intelligence quotients measuring higher in the group which had had surgery. This latter finding was associated with improvement in psychological adjustment and behavior, as well as a decline in maternal anxiety and indulgence.

But other inquiries into the interrelationship of

congenital heart disease and cognitive function have yielded conflicting results. In one such study, the Stanford-Binet test was administered to 60 boys and 58 girls ranging in age from five to ten years, one month before and one month after surgical correction of their congenital defects.¹⁵ In addition, the Wechsler Intelligence Scale for Children (WISC) was administered to the same children six months postoperatively. The WISC, which uses the same materials for children 5 to 15 years of age, has separate tests for verbal and performance skills. The WISC's five verbal tests are designed to measure reasoning, mathematical ability, ability in making comparisons, vocabulary, general knowledge, and common-sense judgments. The tests of performance include understanding of depicted scenes, basic copying, puzzles, detecting the missing parts of pictures, and building blocks into complex designs that stress spatial relationships.¹⁶ Boys with congenital heart disease recorded unremarkable verbal and performance intelligence quotients on pre and postoperative tests. The girls' verbal intelligence quotients were disproportionately low in relation to their own performance IQs, and were significantly lower than those of the boys studied. This is the reverse of the usual finding that girls tend to do their best on verbal tests, and that boys excel on performance tests.

The results of a subsequent study by Cravioto and his colleagues¹⁷ did not coincide with Honzik's findings. Sixty-three acyanotic Mexican children (22 boys and 41 girls) awaiting surgery were individually tested with the WISC. The male children were found to have significantly lower full-scale, verbal, and performance intelligence quotients than the normal comparison group (matched according to age, sex, and socioeconomic status), while the intelligence quotients of the female children differed insignificantly from those of the controls.

Stevenson and his co-workers attempted to assess the impact of hypothermic surgery on the cognitive facility of children with congenital heart disease.¹⁸ Of 32 surviving infants who underwent hypothermic heart surgery for congenital lesions, 21 underwent a battery of formal psychological testing (1 to 80 months postoperatively). The majority of the survivors were found to be of normal intelligence, and causes other than the hypothermia were indicated for the seven sur-

vivors whose intelligence quotients were below normal.

Assessment of Studies

The published studies reviewed herein are individually instructive on certain aspects of the emotional ramifications of congenital heart disease in children, but collectively somewhat skewed in focus. In general, the body of materials appraising the psychological effects of congenital heart defects on the children themselves is characterized by more crucial gaps and more conflicting (and therefore confusing) findings than is the body of material appraising the effects on parents and family relationships arising from the presence of a child with congenital heart disease; and while there has been considerable exploration of the interaction of the mother with the child after the child achieves some mobility and is verbal, much less attention has been given to mother-infant relationships.

How does a mother feel when she gives birth to a blue baby or is told that there is a murmur which may or may not be serious? Does she react with anger at the imperfection, or is she excessively afraid of her child, fearing that she will harm him or expose him to infection if she picks him up to rock him or brings him into the family circle for socialization purposes? Spitz's demonstration that maternal deprivation in the first year of life may affect the infant's ability to thrive leads one to suggest that a mother's reluctance to handle her cyanotic child may delay or prevent bonding, thereby increasing the likelihood that his growth will be retarded.¹⁹ Conversely, a mother, out of excessive anxiety and/or in an attempt to overcompensate for negative and rejecting feelings, may overprotect and pamper her child, or her resentment/anxiety may be expressed through inconsistent and negligent handling of the infant. Interviews with mothers of children with congenital heart disease disclose a recurring theme of guilt in these women and a tendency to invoke a diverse range of causes for their child's handicap—not wanting the child enough, bearing him despite a family history of congenital heart disease (whether recognized or not), the ingestion of drugs, con-

tinued work performance during pregnancy, and insufficient/excessive weight gain during pregnancy.⁶ In this connection, it is appropriate to review what is currently known concerning the etiology of congenital heart disease. Current opinion holds that cardiovascular malformations result not from a single causative factor, but rather from a complex interaction among various genetic and environmental factors. Maternal rubella and the ingestion of thalidomide in the first trimester of pregnancy are two environmental insults that are known to interfere with normal cardiogenesis in man. A single gene mutation may be involved in certain forms of cardiovascular anomalies; the pleiotropic effects of single genes have been cited in other syndromes involving multiple congenital defects.²⁰

The published results of studies undertaken in exploration of the possible relationship between intelligence quotient values and congenital heart disease, as well as of studies seeking to determine the effect of corrective surgery on cognitive functioning, raise as many questions as they answer. Although low IQ scores have been recorded in some afflicted children, both pre and post-operatively, available research warrants the tentative conclusion that (1) congenital heart disease (regardless of hemodynamic severity) does not have any consistently noted relationship to cognitive functioning, and (2) hypothermic open heart surgery does not necessarily have long-term effects on intelligence quotient levels. Aside from the much larger question of whether IQ tests are a valid assessment of cognitive functioning, matters deserving more explicit attention in future psychological studies of children with congenital heart disease include the following: (1) Have some children been assessed as "below par" intellectually because of certain behavioral tendencies arising from distorted self-image? (2) Can extracorporeal bypass circulation, now frequently used during repair of congenital heart defects, have adverse long-term consequences relating to cognitive functioning, and what is the effect of varying intraoperative PaO₂, PaCO₂, and mean blood pressure values? (3) Have all other organic factors that might influence the data, eg, coexisting developmental abnormalities of the brain, such as the cardiofacial syndrome,²¹ been taken into account?

The ways in which a child's self-image, including his perception of his intellectual capabilities,

can be distorted warrant more imaginative concern than they receive from researchers, as well as from cardiologists, pediatricians, and parents dealing with children having congenital heart disease. A surprising number of cardiologists and pediatricians believe, and tell parents, that an asymptomatic or mildly symptomatic child will "never know" that he has a heart impairment unless he is told. This imposed secrecy, combined with a requirement for vigilance, places a particular strain on the parent-child relationship. This consideration aside, the author can state from her experience with [mild] congenital pulmonic stenosis that it is unrealistic to assume that a child propelled through the year-in-year-out ritual of visits to clinics and hospitals does not know that something is awry. His inner self can scarcely remain totally unaffected by the hours of waiting in sterile-looking rooms crowded with anxious parents and sick-to-very-sick children; the repeated batteries of physical examinations and tests performed by a parade of faceless specialists at every level of the medical hierarchy; and those encoded evaluations spoken over his head to his parents at day's end. His confusion is likely to be greater if there are siblings who are not subjected to such attentions.

If a child is not given the opportunity to assimilate the basic facts of his heart disease, however minor his impairment may be on a scale that evaluates candidacy for surgery, he is likely to use his own imagination to interpret the specific nature of his imperfection. If he has a murmur, he is very likely to discover at an early age that what goes on in his chest bears no resemblance to the steady beat in the chest of the sibling or friend with whom he tussles in play. The word "heart" has many important meanings in this culture; although we have progressed beyond Aristotle's belief that the brain is simply the cooling system of the heart, a child exposed to Judeo-Christian teachings and literature is unlikely to regard an abnormal heart as simply a malfunctioning pump. Soul, heart, and brain are used interchangeably in poetry, music, literature, and religious teaching, and the child with a cardiac abnormality is especially likely to consider his heart as the center of his thoughts, of his conscience, of his very being. Whether or not he is born into a family that places significant emphasis on intellectual achievement, he may conclude that what is "really" wrong with him is that he is stupid; such a self-perception would, it seems

logical to reason, affect one's ability to function in testing situations. Among other possibilities, children's recorded self-observations might provide some insights helpful in determining the significance of decreased self-esteem as a factor in low intelligence quotient levels recorded in some cardiac children.

Implications for the Physician

Cardiologists and pediatricians have noted that many mothers, despite explanations to the contrary, blame themselves for their infant's abnormality. Perhaps herein lies a rationale for the frequent complaint made by physicians that the parent seems unable to "hear" a simple explanation of the anatomical problems and activity restrictions involved in a specific form of congenital heart disease. It seems especially important for the physician to make an effort to get at and deal with the mother's guilt and anxiety over her child's defect in view of two consistent findings: (1) the child's emotional adjustment is, to some extent, a function of maternal anxiety (usually manifested by pampering and overprotectiveness), and (2) maternal anxiety is primarily a function of the presence of heart disease rather than its severity.^{1-6,8} The second finding underscores the first, and suggests that the symbolic meaning of "bad heart" should be considered in relation to parent as well as child. In any case, investigation of the mother's affective situation may enhance physician-parent communications. A sound approach might be to ask the mother, "What are your ideas about your child's problem?" thereby rendering to her an empathic space in which she is free to express and experience (and eventually become less fearful of) her own guilt, anger, and anguish. Subsequently, it becomes possible to correct her perceptions, providing this is done in a nonauthoritarian fashion.

Ideally, the physician should also be prepared to deal with the mother's concern that her child's illness may constrict family finances and recreational activities. She may seek advice or reassurance regarding future pregnancies. The mother

may desire to discuss possible difficulty in disciplining the child, his becoming the "center of attention" and the effects of this, and/or his poor prognosis, if such be the case, on the rest of the family. Brief written statements to the child's school nurse and dentist concerning limits on physical activity and advisability and instructions regarding the periodic use of antibiotics as prophylaxis against infective endocarditis will spare the parent the tricky task of having to carry messages between health-care professionals, and are generally appreciated by all concerned. Pediatric cardiologists have observed that the child with congenital heart disease frequently attempts to overcompensate for his physical defect and may tend (overtly or covertly) to overexert himself. Hence, the physician may need to work to uncover the child's actual activity level. It is probably better for the physician to discuss any limits on physical exertion with both parent and child (depending on the child's age), rather than to instruct the parent to tell the child.

Physicians tend to underestimate the impact of cardiac catheterization on both parent and child. Although this is a routine procedure for the physician, it is not for the young cardiac patient or his parents.¹³ The child may perceive it as an invasive and unnecessary exploration of his body of immediate benefit only to the physicians concerned, not as a step that may lead to a "fixing" of his impairment. Furthermore, for both parent and child, the catheterization is the initial trauma both in the physical and psychological sense, preceding any possible surgery.

There are a number of ways in which health-care professionals could undertake to "hear" the child tell his own story about his heart. Two simple ways are: (1) question the child (saying "Why do you think your mother brings you to the clinic?" is a good place to start); (2) make direct observations and interpretations via play therapy. The aid of liaison psychiatric personnel may be invaluable, especially if play therapy is employed. The child's misperceptions, if any, need continual reassessment and gentle correction. This process must begin, however, with an acceptance by cardiologists and pediatricians that one does not avoid "cardiac neurosis" by assuming that one can keep secret from a child a physical fact that profoundly affects how he is treated by others and how he feels within himself.

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