Middle Articles

CONTEMPORARY THEMES

Impact of Congenital Heart Disease on the Family: Preliminary Report

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"The doctor says she's got a bad heart," said a mother, "but it's us who suffer, not her." How much does the family suffer?

Firstly, we wanted to determine whether congenital heart disease has an appreciable impact on the family of the affected child. Secondly, if it has, to assess how the impact is influenced by the cardiac disorder, by the characteristics of the family, and by medical management.

The aim was, so far as is possible, to check clinical impressions with hard facts and statistically valid data—"to measure the measurable and make measurable the immeasurable."

Material and Methods

The study was based on 100 randomly selected children with congenital heart disease of all ages from infancy onwards. They were under the care of many family doctors and several consultants. Thirty-nine lived in Bristol, the remaining 61 in other parts of the South-western Region. The diagnoses, operations, and deaths are summarized in Table I.

TABLE I.—Cardiac Malformation in 100 Children

Diagnosis	No.	Fully Investigated	Additional Anomalies	Operation performed*		Died
				Complete	Partial	
Ventricular septal defect	25	14	8†	10	3	1
Atrial septal defect	18	13	5	9	2	
Tetralogy of Fallot	15	10		6	4	3
Patent ductus arteriosus	31	2	?	12		1
Pulmonary stenosis	7	6	3	4	1	
Coarctation of aorta	6	6	?	2	1	1
Aortic stenosis	4	1				
Miscellaneous multiple	12	11			2	4

* In several cases operation has since been performed.

† Including five with pulmonary stenosis.

In addition to hospital consultations 70 home visits were paid. One of us (I. W.) interviewed all the mothers, usually on two or more occasions, and 54 fathers (25 apart from the mother). Standard question sheets were used and assessments were made on predetermined criteria, using point-scales where possible. Supplementary inquiries were made of doctors, ward sisters, and schoolteachers. The information was coded and recorded on punch cards. The measurable data have been analysed statistically.

Impact on the Family

Twelve families are here excluded because the diagnosis had been made too recently for the dust to settle, and the analysis is based on the remaining 88.

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Family as a Whole

Family balance upset (e.g., father changed job, family moved house, rooms rearranged) ...	54%
Social life modified (e.g., outings and parties restricted, holidays modified) ...	36%
Extra expense ...	45%

Parental Reactions

1. Immediate "shock reaction":¹ Mothers excessively disturbed ... 39%
2. Subsequent adjustment:
 - (a) Unsatisfactory relationship with child:

Mothers	68%
Fathers	42%
 - (b) Mothers dissatisfied with consultations ... 62%
 - (c) Fathers developed psychosomatic reactions ... 12%
 - (d) Decision to have no more children ... 30%

Sibling Reactions (based on 70 families with 155 siblings at risk; 18 families were excluded because there were no available siblings)

Families Affected	
Behaviour problems alone	27%
Psychosomatic disorders alone	13%
Both together	24%

(An impression that siblings were relatively neglected could not be assessed numerically.)

¹ 44% of mothers used the term "shock."

Role of Congenital Heart Disease

Though disorders of the heart were believed by many parents to carry profound emotional implications, a comparison with other serious disorders would be necessary to assess whether the impact of congenital heart disease is unique or differs in degree. Nevertheless, it seems relevant that at paediatric outpatient clinics, at the first attendance of children with suspected heart disease, the child and mother were accompanied by the father in 50% of cases, as compared with 17% of children attending for noncardiac conditions.

The severity of the malformation in congenital heart disease appeared to play some part in determining the force of the impact. It was not possible to separate the many contributory factors, and our overall figures showed only trends, so we examined the extreme ends of the scale as regards severity.

The families of 12 children with incurable congenital heart disease in the series were compared with those of 12 children (not included in the series) in whom an original diagnosis of mild or possible congenital heart disease had been discarded after some years of hospital attendances. The clear-cut differences are shown in Table II.

TABLE II.—Severity of Congenital Heart Disease and the Family

	Least Severe	Most Severe
Family balance upset	1	10
Social life modified	0	7
Siblings disturbed	4	9
Extra expense	0	5

Role of the Family

The focus was mainly on the parents, particularly the mothers as key figures in family relationships. According to their reactions and attitudes parents were placed in groups. Firstly, those showing disturbed relationship with the affected child (excessively overprotecting in most, rejecting in a few) were termed "specifically overreacting" and were compared with those whose relationship was judged to be well adjusted. Secondly, on the basis of their attitudes to life situations in general (as distinct from that associated with the child's disorder) parents were grouped as "generally immature" or not.

From comparisons on 90 points and analysis of the many correlations, the statistically significant differences which

TABLE III.—Comparison of Specifically Overreacting and Adjusted Mothers

	Specifically overreacting	Adjusted	χ^2 Values	D.F.	Probability
Total	60	28			
Mature	24	24			
Not mature	36	4	16.091	1	<0.001
Satisfied with interview	15	18			
Not satisfied	45	10	10.951	1	<0.001
Family balance upset	42	6			
Not upset	18	22	18.166	1	<0.001
Prone to anxiety	42	9			
Not prone	18	19	11.228	1	<0.001
Unexpected reaction to diagnosis	33	5			
Expected reaction	27	23	10.735	1	<0.01
Extra expense	33	7			
No extra	27	21	6.930	1	<0.01
Social life affected	27	5			
Not affected	33	23	4.962	1	<0.05
Leaves child with neighbours	37	24			
Does not	23	4	4.122	1	<0.05
Husband specifically overreacting	26	4*			
Not overreacting	34	20	4.212	1	<0.05
Sibs allowed to rough-and-tumble with patient	9	12†			
Not allowed	38	11	6.525	1	<0.05

* n = 84. † n = 70.

TABLE IV.—Comparison of Generally Immature and Mature Mothers

	Generally Immature	Mature	χ^2 Values	D.F.	Probability
Total	40	48			
Prone to anxiety	33	18			
Not prone	7	30	18.132	1	<0.001
Unexpected reaction to diagnosis	25	13			
Expected reaction	15	35	11.154	1	<0.001
Specifically overreacting	36	24			
Not overreacting	4	24	16.091	1	<0.001
Has outside interests	5	19			
Has not	35	29	6.761	1	<0.01
Below average intelligence	19	9			
Not below	21	39	8.313	1	<0.01
Family balance upset	28	20			
Not upset	12	28	7.064	1	<0.01
Leaves child with neighbours	23	38			
Does not	17	10	4.816	1	<0.05
Social life affected	20	12			
Not affected	20	36	5.893	1	<0.05
Father generally immature	22	16*			
Father mature	16	30	4.487	1	<0.05

* n = 84.

emerged are summarized in Tables III and IV. These show the correlations found to be statistically significant. The factor of "specifically overreacting" correlated at the level of $P < 0.001$ with general immaturity of mother, satisfied with interview, family balance upset, and prone to anxiety; at the level of $P < 0.01$ with unexpected reaction to diagnosis and extra expense; at the $P < 0.5$ level with social life affected, leaves child with neighbours, and sibs allowed to rough and tumble with patient.

The factor of "general immaturity" correlated at the level of $P < 0.001$ with prone to anxiety, unexpected reaction to diagnosis, and specifically overreacting; at the $P < 0.01$ level with outside interests, below average intelligence, and family balance upset; at the $P < 0.05$ level with leaves child with neighbours, social life affected, and father generally immature.

Miscarriages and Deaths in the Family.—There were significant correlations between sibling disturbances (see above) and a family history of miscarriages or death of a sibling, as shown in Table V.

TABLE V.—Correlations of Disturbances in Siblings

	45 Families with Disturbed Siblings	25 Families with No Disturbed Siblings
History of miscarriages	33%	4%
History of sibling death	18%	4%

Medical Management

The patients were under a number of doctors, and it was apparent that they were sensitive to varying qualities in medical management. It was obvious that many parents had taken away from the consultations impressions very different from what the doctors had meant to convey. These differences were, however, difficult or impossible to quantify. It will be appreciated that we were considering how actions and words were accepted and understood.

Delay and Uncertainty

Delays in the confirmation of a diagnosis or in operation tended to be associated with overanxiety and disturbances in family patterns, as shown from 48 operated cases in Table VI.

TABLE VI.—Interval Before Operation and Parental Overreaction

Interval	Overreaction	
	Mothers	Fathers
Less than 1 year (30)	50%	27%
More than 1 year (18)	67%	50%

Many parents spoke of uncertainty, particularly regarding diagnosis, and its disturbing effects. Changes in diagnosis by one doctor or its disturbing effects in terms used and restrictions advised by different doctors and nurses had a similar effect (15 cases). There was a similar reaction when a child was admitted, as the parents thought, to hospital "for a few days" and in fact stayed for weeks or even months.

"At Risk" Families

Among these are included families in which parents are "specifically overreacting" or "generally immature" (see above) or where miscarriages or death of a sibling have occurred. Our group of "specifically overreacting" mothers included five highly intelligent women and three trained nurses, and such mothers may be "at risk." In "at risk" families a high

standard of medical management and communication appears to be particularly important.

Communication

Only 42 of 100 mothers were fully satisfied with the diagnostic consultations, 26 were incompletely satisfied, and 32 were dissatisfied. A high proportion (75%) of "specifically overreacting" mothers were not completely satisfied, but one-third (36%) of the well-adjusted mothers made similar complaints.

At consultation and at other times a good deal of misunderstanding and distress was provoked by inadequacies of communication, evidently unsuspected by the doctors concerned. The discontent of parents was directed not at family doctors but at hospital staff. Interestingly, surgeons and nurses were rarely targets for criticism, apparently because they "did something." In contrast, physicians, who were thought to do nothing except explain and give advice (some did this much better than others), were criticized for what was believed to have been said and the circumstances in which this was done. It was clear also, from others who were present, that some of what was said failed "to register." Physicians were also blamed for delays (planned or accidental), alterations of arrangements, and administrative mishances.

The two-way process of communication was particularly liable to suffer at times of crisis. On the parental side it seemed frequently to be impaired by anxiety, which often led to misinterpretation or a failure to take in what was said; and on the other side by professional caution, which blunted the assurance that parents needed, or by the doctor's preoccupation with the physical aspects of the cardiac disorder.

Doctors have a viewpoint too, but here we give samples only of remarks made by parents. "He listened to the heart, but

he did not have time to explain and I did not like to ask." "The doctor said she had a hole in the heart and he would see her in a year." "We saw a different doctor each time, and they did not seem to know what we had been told." "We waited two years with his bag packed to go into hospital." "We were sitting in the corridor and the doctor stopped and said it was all right."

Conclusions

Congenital heart disease in a child often produces a harmful impact, material and emotional, on the family.

The effects of the impact are determined largely by parental characteristics, and certain families are particularly "at risk." Other influences are the severity of the cardiac disorder and the quality of medical management and communication.

In this preliminary report we have emphasized not the good results that were expressed in satisfactory adjustment and appreciative remarks but the incomplete or bad results reflected in family disturbances and criticisms. Some of the criticisms can be attributed to the attitudes of parents rather than of doctors, but it is their families which need most understanding and help.

From our study it is clear that the harmful impact of congenital heart disease could be lessened, and, in terms of the child and family rather than the heart alone, the results of treatment could be improved.

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MEDICAL HISTORY

Slitting of Letters for Disinfection in the Eighteenth Century in Malta

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The purpose of disinfecting correspondence was to prevent the importation of pestilence into the Maltese Islands, as in the past it was believed that the "contagion" of plague could attach itself to paper (Cassar, 1962, 1965).

Arrangements for carrying out the disinfection of letters were in existence in Malta by 1678—that is, two years after the worst visitation of plague in the history of the Maltese Islands. It has been stated that the means employed for this purpose at that time are unknown, and that no precise documents have been found from which one can deduce the nature of the mail-disinfection methods of the seventeenth and eighteenth centuries in Malta. It has been suggested that by 1787, over a century later, the process used in Malta was the same as that then prevailing at Marseilles—that is, incising the letter (*entaïlles*) and soaking it in vinegar. The earliest instance,

however, which has been quoted of the incising of correspondence for purification in Malta belongs to 1809. The evidence consists in a letter that passed through the Island in that year on its way to Great Britain from Smyrna (Carnevale-Mauzan, 1960a).

I have recently come across a set of manuscripts which, though not dealing directly with the subject, contain references to the mail-disinfection procedures in use in Malta in the eighteenth century. So far as I am aware these manuscripts have never been published. It has therefore been thought worth while to place on record those parts of the documents that concern the purification of letters (Archives 6464, Royal Malta Library, Valletta).

The earliest allusion is to the year 1720. On 12 September of that year a series of regulations were issued by the Deputation of Health of the Order of St. John relating to the quarantining of vessels, the control of ship-to-shore communication,

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