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PSYCHOLOGICAL ASPECTS OF CONGENITAL HEART DISEASE*

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During the last few years, a great and sudden change in the prognosis of many congenital heart lesions has been brought about by dramatic advances in cardiac surgery. Children who were previously condemned to a limited life of invalidism can now often be restored to healthy activity and a normal life expectancy.

Now that satisfactory surgical techniques have been perfected it is most important that every possible care should be taken to ensure that the maximum advantage is derived from these operations. A new era has been opened in this field and, with the advance, certain problems for which there was previously no particular reason for concern have now to be faced. The excitement and drama have quite naturally been centred upon the activities in the operating theatre and there has been a tendency to overlook other aspects of the handling of these cardiac children.

There are several psychological considerations pertaining to the management of these patients which, though hitherto neglected, deserve most serious attention. Many of these problems arise during the years before the child is operated upon. Before discussing these, however, I propose to devote a little attention to the question of psychological handling at the time of operation.

AT THE TIME OF OPERATION

When a child with congenital heart disease is admitted to hospital for operation, the attention, thoughts and efforts of the surgeon are, of course, directed to the nature of the cardiac lesion and to the necessary steps towards its surgical repair. Unless the surgeon and his team have become psychologically orientated, there is a tendency to diagnose and treat the anatomical defect without giving adequate regard to the child's intellectual, emotional and personality structure. Such an approach fails to recognize the importance of treating a cardiac child as a total individual. The mere act of hospitalization, the surgical assault, the post-operative pain and discomfort, and the sudden removal of parental love and care, together constitute a psychological trauma of considerable magnitude. If this fact is not given the attention it deserves, the fundamentally important emotional security of the child is threatened and this, I venture to suggest, will interfere with satisfactory post-operative progress.

A few months ago, I had the opportunity of observing the methods employed at the cardiac surgery unit in the Mayo Clinic in Minnesota, USA, under the leadership of John Kirklin. Kirklin is acutely aware of the importance of a correct psychological approach in the handling of his surgical patients. He obviously considers this approach to be an essential part of surgical management and insists on its thorough application. In dealing with this aspect of congenital heart disease, I can do no better than describe my personal experience of Kirklin's routine:

Before the child's admission to hospital, Kirklin makes a point of establishing a friendly and reassuring relationship with the child. Before discussing the operation with the patient, he ascertains from the parents what they have already done towards preparing the child psychologically for the ordeal that lies ahead. He then proceeds to tell the patient all about the operation. The exact form which this discussion takes will depend upon the age of the patient, and other circumstances, but subterfuge is always avoided. The surgeon explains that there is something wrong that needs to be put right by an operation which will make the patient perfectly normal like all other children. The child is reassured concerning his parents' presence in the hospital throughout the operation and afterwards. The method and purpose of anaesthesia is carefully explained. Post-operative conditions are then outlined. He is warned to expect a few days of pain and discomfort, but is reassured of the minor severity of the ordeal. The necessity for post-operative restriction of food and fluid by mouth is explained and this leads on to the story of intravenous feeding. The child is warned about his wound, the stitches and drainage tubes. The purpose of an oxygen tent is explained and, in these modern times, it is usefully compared with the interior of a space ship. Kirklin has the ability to make the child feel that he is in for some great adventure, rather than an ordeal of which to be afraid. He is most sympathetic in his manner and concludes by inviting the child to ask questions on any points that he may or may not have raised.

Having done his utmost to reassure the child by eliminating as far as possible elements of mystery and fear, he then gives his attention to the parents. They, too, are reassured and invited to ask questions. If the patient is to be brought into hospital on the evening before the operation, the parents are requested to remain with him until he is asleep. The following morning, they must be with the child during the half-hour period before his removal from the ward to the operating theatre. After the operation, as soon as the patient has been bedded and has regained consciousness, the parents are instructed to come to the bedside. It is considered most important to reassure the child that his parents have not abandoned him at this crucial stage. Visits to the bedside are curtailed to about 5 minutes but are repeated regularly once an hour for at least 48 hours. Once the child has survived this critical post-operative period and is making satisfactory progress, visiting continues on a more casual and less frequent basis.

During the first week or two after operation, these patients suffer a good deal of pain and discomfort. Not unreasonably,

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they sometimes develop intense feelings of resentment towards the parents for having landed them in this predicament. Parents are warned of the possibility of this emotional reaction and are so enabled to cope with it, with a minimum of alarm and anxiety.

Kirklin's psychological approach, based on common sense, is simple and easily applied. At the same time, it is positive and well directed. Surely its value is beyond dispute.

THE YEARS BEFORE OPERATION

The cardiac lesion is usually recognized at a fairly early stage and from then onwards the heart condition is kept under constant observation and assessment. The assessment, however, is to be considered grossly deficient if it does not include an evaluation of the child as a total individual. These children are subject to profound and most important psychological reactions to which the numerous writings on congenital heart disease make no significant reference.

These psychological problems may arise from two main sources, viz. (1) the physical handicaps produced by the cardiac disease, and (2) faulty parental attitudes.

Physical Handicaps

From the day of its birth every normal child sets about the task of establishing a psychological goal of emotional security. Anxiety-provoking situations are encountered all along the line of normal emotional development, and it is the way the child deals with this anxiety that determines his ultimate personality structure. In the child physically disabled by congenital heart disease, the anxiety-provoking situations become magnified and his ability to deal with them reduced.

For every infant, the first natural source of emotional security is found in satisfactory feeding from its mother's breast. An infant with cardiac disease may encounter difficulty with feeding and at once becomes the victim of anxiety. The anxiety produced by a perpetual struggle for breath is readily understood. The strain and exhaustion which accompany the passing of excreta and the dyspnoea that may interfere with sleep add to the infant's fears. As he grows older, new difficulties arise. At every stage he finds himself at a disadvantage. The development of motor power, coordination of movement, and ultimately walking, all represent an uneasy struggle. Every new phase calls for a supreme effort and nothing comes easily to the cardiac child. The world appears unsafe, threatening and frightening.

His daily activities soon become involved in the battle to keep up with other children. To a greater or lesser degree, he finds himself failing in this task. His activity is restricted, his ability to take part in games is limited, and his general relationship with other children is thwarted by obvious difficulties.

Sibling rivalry. It is common knowledge that problems of emotional maladjustment very often arise out of rivalry and jealousy between different members of a family unit. It is not necessary to elaborate on the various types of emotional situation which might arise; I only wish to point out that the problems of sibling relationships tend to become accentuated and complicated for the cardiac child, for instance, when he finds that he cannot compete with the physical attributes of his younger brother. A consideration of the constitution of the family must never be excluded in the assessment of the emotional problems of a cardiac child.

Psychological results. Thus, once a cardiac child is physically handicapped, psychological handicaps must follow. Very soon, unhealthy psychological defence mechanisms may develop. There are many ways in which these children may try to defend themselves against anxiety. Some may deal with the problem by abandoning the struggle and avoiding situations likely to confront them with anxiety. These children become increasingly asocial and withdrawn and adopt the attitude, 'I cannot manage, leave me out of it'. They may gradually become grossly introvert personalities, unable to establish normal interpersonal relationships.

Another group may react to their anxiety with a markedly over-dependent attitude towards their parents. They cling to their mother and become acutely anxious if threatened with any attempt to emancipate them from their emotional dependence. These are the children who are afraid to be left alone, cannot face going to school and generally fail to achieve that degree of emotional independence so essential to the satisfactory integration of any personality.

Resentment, frustration, jealousy, and an inability to compete with other children, may result in various forms of aggressive behaviour. Temper tantrums, crying spells, and other attention-seeking mechanisms may develop. More direct expressions of anxiety such as thumb-sucking, enuresis, nightmares, and nail-biting are often encountered.

Parental Attitudes

The recognition of the psychological reactions of these children leads naturally to a consideration of their parents. An adequate appreciation of the stress and strain to which these parents are subjected, and an understanding of their emotional reactions to the situation, become fundamentally important to a proper understanding of the psychological problem which I am attempting to outline.

When a mother learns for the first time that her child is suffering from congenital heart disease, she is obviously being confronted with a psychologically traumatic experience of considerable magnitude. Her immediate reaction and her subsequent behaviour and attitude towards her child will depend on a host of factors. If she is an emotionally well-integrated personality she will deal with the situation with a minimum of emotional disturbance; not so if she is already neurotically orientated. Her intelligence will be of some importance but of less significance than her emotional make-up. In addition to these personality factors, there will always be a variety of environmental circumstances which will influence the situation.

Feelings of guilt. In a great number of psychiatric disorders, guilt is the seed from which a host of emotional disturbances germinate. The problem under discussion is no exception. When a mother learns of her child's congenital affliction, one of her first thoughts is to wonder whether she might be in any way to blame. It is, after all, not easy to accept that cardiac malformations 'just happen'. The idea that the child's condition may represent some form of punishment readily asserts itself. A woman with an over-developed super-ego, particularly, will tend to find what in her mind would seem to be reasonable explanations for the calamity which has befallen her. In surveying her pregnancy period she will find evidence on which to pronounce herself guilty. Minor quarrels with her husband, the fact that she had not rested as she had been advised, or not attended adequately to her diet, and many other trivialities come rushing into her mind to assume tremendous significance and add fuel to

the fire of guilt. Guilt is readily aroused in the woman who has made it clear from the start of her pregnancy that she did not want this child (a reaction from marital strife, financial insecurity, or other reasons). The woman who gives birth to a daughter after a persistent and pathological insistence that she must have a son falls into a similar category.

The arousal of severe guilt feelings is then a not infrequent occurrence in the mothers of these children, and to a lesser extent in the fathers. Severe depressive reactions may develop as a consequence of these feelings of guilt.

Anxiety. It is perfectly normal for parents to react with anxiety concerning their child's illness. It is abnormal only when this assumes pathological proportions. It does not always flow directly from feelings of guilt; in many instances it simply represents an accentuation and reinforcement of previously established neurotic anxiety patterns. In such cases, a great deal will depend upon the nature of the interrelationship between the present anxiety situation and the psychodynamics underlying the previously existing anxiety pattern. In these unfortunate parents, the problem of their disabled child becomes all-absorbing, influences their every activity, and precludes them from anything resembling a normal way of life. The fear of impending disaster is ever with them.

Parental behaviour. The obvious question of how guilt feelings and pathological anxiety are likely to influence the parents' behaviour towards the child remains to be answered. In this connection, parental attitudes of rejection and overprotection become particularly prominent.

Rejection may express itself quite openly, when the parent will display an obvious lack of affection for the child. An unreasonable demand for perfection in behaviour and a generally over-critical attitude may develop. Failure is not tolerated and expressions of hostile aggression towards the child will be encountered. In extreme cases, emotional outbursts may arise during which such remarks as 'I hate you; I wish you were dead' will emerge from a neurotic mother who cannot escape from the torments of her inner conflicts of guilt and anxiety.

Gross *over-protection* is common. This faulty attitude may be the direct outcome of pathological anxiety or may represent a cover-up for a repressed attitude of rejection. It is a great temptation to over-protect a disabled child and it is only the parent who has made a completely adequate adjustment to the situation who will avoid falling victim to this pitfall. Once a mother's attitude towards her child becomes influenced by her own emotional maladjustment, extreme degrees of over-protection will occur. The children who become victims of such over-protection are kept 'wrapped in cotton wool', protected from every possible stress, strain and frustration, and deprived of the chance of a development of emotional independence.

It should not be necessary to belabour the fact that attitudes of rejection and over-protection are likely to produce in the child profound emotional disturbances and markedly abnormal personality integration. To discuss the details of the effects of these abnormal attitudes would involve an unwarranted description of a host of emotional reactions that might be encountered in any child subjected to these unfavourable influences.

PSYCHOLOGICAL HANDLING OF THE CARDIAC CHILD

It is hoped that the value and, indeed, the complete necessity of approaching the cardiac child as a *total individual* has been satisfactorily established. The serious consequences of emotional maladjustment and defective personality integration in these children cannot be over-emphasized. Consider the child who goes to operation with an already seriously damaged personality. The surgical repair of the cardiac lesion might be completely successful but the patient remains psychologically crippled. Instead of being made fit for a normal life ahead, he runs the risk of an unsatisfactory school and employment record, a poor future marital adjustment and generally unsatisfactory interpersonal and social relationships. In this way, the success of cardiac surgery becomes intimately related to the patient's satisfactory pre-operative psychological development.

The first essential to the correct psychological handling of congenital heart disease must be a thorough understanding and appreciation of the precise nature of the relevant psychological problems, as well as their possible implications and consequences. It is hoped that in following the course of this discussion, such understanding has been achieved.

By quoting the example of Kirklin at the Mayo Clinic, I have pointed out the steps which can be taken to overcome psychological difficulties pertaining to cardiac surgery itself. I only wish to draw the attention of thoracic surgeons to the efficacy of the approach which was outlined and suggest its adoption in a complete or modified form.

My recommendations concerning the psychological handling of the cardiac child during the pre-operative years are directed to the general practitioners, the paediatricians and the cardiologists. The aim which I have in mind is the prevention of the development of abnormal emotional reactions, disturbed behaviour, and defective personality integration, which I have shown can arise in association with this condition. I believe that there is a tremendous amount that can be done for these children in this respect. They require constant encouragement and reassurance. I want to stress that the question of whether a cardiac child will make a satisfactory emotional adjustment rests essentially in the hands of the parents. For this reason, it is towards the parents that psychological assistance should be principally directed. It is most important that recognition should be given to the value of devoting time and attention to these parents. If this is not done, it is quite impossible to treat the total problem entailed in any case of congenital heart disease.

The family. Once the diagnosis has been established, an attempt should be made to make a simple assessment of the family unit. In order to do this, a single short interview with each sibling would be required. Depending on circumstances, it may be necessary to interview the father on more than one occasion. The mother will require the most time and attention, the extent of which will depend on her specific needs for psychological assistance. This assessment of the family unit could be carried out in the space of very little time, and it would prove invaluable in gaining an insight into the problems not only of the patient but also of the parents.

I am convinced that thorough attention to the mother's difficulties would be richly rewarded. A few remarks on the aetiology of her child's condition, together with a little

patience in answering her questions on that score, could do a tremendous amount towards dispelling unnecessary feelings of anxiety, rejection and guilt. Misconceptions should be eradicated from the start. The mother should know that congenital heart disease is not uncommon, that medical science has made tremendous advances in this field, and that the treatment of this condition is often entirely successful. This preparatory reassurance would be most important during the initial distress from which the parents suffer.

The nature of the various emotional reactions and behaviour patterns that might arise in her child, and reasons for them, must be given adequate explanation. She must be advised how best to handle these disturbances. The problems of sibling rivalry must be explained and the dangers of over-anxiety and over-protection carefully elucidated. The mother should be encouraged to attend for periodic discussions of her problems to ensure an adequate control over the patient's emotional development.

The amount of psychological assistance which a mother may require will naturally vary with individual demands. If evidence of marked emotional disturbance in the parents is forthcoming, regular psychotherapeutic sessions will become necessary. The presence of grossly neurotic reactions would call for psychiatric aid.

CONCLUSION

I have no hesitation in expressing the view that a cardiac clinic is falling short in its responsibilities if it fails to give consideration to the psychological problems which I have outlined.

There remains one further point to be clarified. This discussion has been confined to psychological aspects of congenital heart disease, but it may be considered that a good deal of what has been said could be equally well applied to other conditions. This is in fact the case. The example of congenital heart disease has been used to draw attention to the possible importance of psychological aspects of organic disorders and to emphasize what I like to refer to as a total approach to medical problems. I hope I have at least succeeded in stimulating an interest in an approach which I believe in all sincerity to be a correct one.

SUMMARY

Attention is called to the importance of psychological considerations in the management of children with congenital heart lesions.

Reference is first made to the importance of these considerations at the time of operation on the heart.

The psychological problems of the period before the operation, from the time of birth, are then dealt with. These problems arise (1) from the physical handicaps produced by the cardiac disease, and (2) from faulty parental attitudes, and they are considered in some detail under these headings.

A faulty approach on the part of the mother may be due to feelings of guilt or to pathological development of the normal reactions of anxiety.

Abnormal parental behaviour may take the form of a hostile attitude to the child or to over-protection.

The details of psychological management are considered and the importance of this aspect of treatment is stressed.

Finally, reference is made to the possible importance of the psychological aspect in other organic disorders—the 'total approach' to medical problems.