Chapter 10
Psychological Aspects in Congenital Heart Disease: A Lifelong Perspective

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10.1 Introduction

In order to explore this topic, the divergence in the expectations regarding the education and counseling that should be provided to parents of children with congenital heart disease (CHD) in both the prenatal and neonatal period by cardiologists [1] will be described. This will be followed by the description of the psychological functioning of patients with congenital heart disease from childhood to adulthood [2, 3].

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G. Butera et al. (eds.), *Cardiac Catheterization for Congenital Heart Disease: From Fetal Life to Adulthood*,
DOI 10.1007/978-88-470-5681-7_10,

10.2 The Importance of Information Provided by the Cardiologist in the Prenatal and Neonatal Phase

- In the literature on this topic, it is outlined that there is a discrepancy when it comes to the importance and relevance on which information needs to be given in the prenatal phase and the neonatal period between the cardiologists and the parents of children with CHD, although there was also an agreement on what needs to be known between the two groups.
- It could be possible that an increase in prenatal diagnosis of CHD could be connected to a rise in decisions to terminate pregnancy, and therefore it becomes particularly crucial to know what and how much the parents want to know and how much they want to communicate.
- Interestingly, the factors considered in deciding whether to continue the pregnancy of a known fetus with CHD differed according to the two groups (parents and cardiologists). Whereas both groups considered the quality of life of the child and the survival into adulthood, for the cardiologist group, the deciding factors were also a potential for neurodevelopmental delay and the severity of the CHD. On the other hand, the factors which also lead to deciding against pregnancy termination of the parents were moral/religious beliefs and survival into birth.
- During the prenatal phase, both physicians and the parents felt that parents should be able to name the heart condition and understand it, what is to be expected in the first hours of life, survival probability at birth, childhood and adulthood comorbidities, whether there were possibilities of not intervening medically after birth, and how to obtain additional emotional/psychological support.
- During this phase, the parents ranked the following issues as being of higher importance than the cardiologist: number of

lifetime surgeries needed, potential need for transplant, exercise limitations, and potential for child to have his or her own baby with CHD.

- In the neonatal phase, both groups agreed that the parents should be able to name the heart lesion, identify who their cardiologist and pediatrician are, the discharge medications, comorbidities, when to seek medical attention, and cardiopulmonary resuscitation training.
- On the other hand, the issues which the parents ranked as being more important than the cardiologist though they would be in the neonatal phase were why the child has CHD, why he or she needs surgery, ability to explain the CHD to a doctor, and follow-up needed.

10.3 Psychosocial Adjustment and Quality of Life in Children and Adolescents with Congenital Heart Disease

- In a literature review conducted in 2009, the psychological aspects in children and adolescents with CHD relating to outcomes after open heart surgery were considered [3]. The review took into consideration studies assessing psychological adjustment (assessed by semi-structured interviews, proxy reports administered to parents and teachers, and self-reports) and quality of life.
- When it comes to long-term psychological adjustment as assessed by the parents, it was reported that psychological maladjustment was present in a considerable proportion of these children and that this proportion is comparable with other children with chronic illnesses (who, when compared with the children in the general population, have a twofold higher risk of having a psychiatric diagnosis).

- Parents also report the operated children as displaying behavior which is outside the normative range and as having more psychological difficulties when compared to the controls (except for children with surgically corrected transposition of the great arteries).
- On the contrary, the proxy reports done by teachers reported that psychological functioning and behavior of CHD children were similar to the ones of healthy controls, which could either mean that these difficulties are more difficult to detect in a school setting or that parental anxieties influence the way these parents perceive their children.
- There are fewer self-report studies on the psychological adjustment in children after cardiopulmonary bypass surgery, which do not report differences between children with operated heart defects when compared to reference group, contrasting the proxy report studies on parents. Two studies on samples which included a large percentage of adolescents reported a significant degree of self-reported behavioral problems, suggesting that there might be difficulty in puberty for these patients possibly linked to increasing academic demands.
- Also when it comes to quality of life, impairments tend to be reported more by the parents than the patients themselves.
- Although current data regarding risk factors for psychological functioning and quality of life in children with CHD is insufficient and conflicting, the cardiac diagnosis in itself does not seem to be a risk factor for psychological maladjustment after cardiac surgery.
- One child-specific risk factor which has been consistently found is developmental delay; however, this applies to proxy reports done by the parents and are not confirmed by self-report studies.
- The actual parents of children with operated heart defects might directly impact the children's long-term quality of life and psychological adjustment; however, more research is needed on this aspect.

10.4 Psychological Functioning in Adults with Congenital Heart Disease

- In a current review, the focus was on the psychological functioning of grown-up CHD patients with a special attention to the link between medical and other variables and the psychological functioning.
- In some studies in the review, it was underlined that the CHD population has similar or even better psychological functioning than the healthy reference population – possibly because they have acquired a higher sense of coherence, due to the constant dealing with physical limitations and difficulties. The types of medical care available in different countries could also impact these patients' well-being.
- It could also be that denial and high achievement motivation could have influenced self-report data.
- Levels of anxiety and depression are similar to acquired cardiac populations – which is probably the best comparison available.
- It is important to note however that in a few studies where in-depth clinical psychological and psychiatric interviews were utilized, patients who were assumed to be well adjusted reveal to experience psychological and psychiatric difficulties and to be undertreated.
- Most of the studies available indicated that psychological functioning in this population is not related to medical variables such as diagnosis and physical status. The variables that result as being predictors of psychological distress reported by this population pertain to their subjective experience and result as being:

    - Loneliness
    - Fear of negative evaluation
    - Imposed limits
    - Low capacity for physical exercise
    - Perceived health status

10.5 Tips and Considerations on How to Approach Families and Patients

- These families and patients have to deal with many issues which often begin during the prenatal phase and which have an impact on how the developmental tasks are dealt with. Pediatric cardiologists often find themselves having to communicate difficult news which entails having to deal with strong emotions, and the integration of psychologists in the medical team can provide the necessary support in order to handle particularly difficult situations and to provide psychological support to the families and the patients when required.
- It is also particularly useful to have a connection with non-profit associations which provide peer to peer support. The parents might be relieved to be able to meet adults with the conditions their children have and also the adolescents and adults can gain great benefits from meeting people with similar conditions and participating in events created by these associations.
- It is indicated that the parents would like to have more information than the cardiologists think that is necessary on a variety of topics. It is possible that there is a tendency of the cardiologists to believe that it is important not to give excessive information which could worry and overwhelm parents. On the other hand, it seems that parents seem to be willing to know more about their situation to prepare psychologically and also to make adequate decisions.
- It is therefore important for the cardiologists to customize the relationship with the parents and the patients, according to the situation the parents are in and the age of the patients, their wishes about the amount of information they would like to receive, and also their psychological and religious necessities.
- When handling the families, it is important to bear in mind that the parents and the patients themselves often have a

completely different approach to the illness. For example, someone born with a chronic illness is somehow used to that condition and for them it is a situation of "normality." For the parents, this is very hard to conceive – and this is supported by the divergence in data when it comes to the psychosocial adjustment and quality of life in children and adolescents with CHD.

- When it comes to adolescents and adults, it is important not to assume that a cardiac condition and severity of disease are automatically correlated to psychological distress, which is more likely to be caused by factors of a psychological nature and a low capacity of physical exercise.
- Finally, it would be ideal for medical and nursing staff to dedicate some time for training in communication skills and also for them to have moments of support in order to prevent burnout symptoms from emerging.

10.6 Conclusions

In conclusion it is essential for cardiologists to spend some time to enquire about how much information parents and also the patients themselves when they are older would like to know and to also consider their psychological needs and belief systems in order to be able to provide an adequate and efficient communication.

References

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