

Research Article

Difficulty of Announcing Congenital Heart Disease in a Child in a Hospital Setting in our Context

Soundousse Salimi, Angela Kibangou^{*}, Nisrine EL Marzouki, Chrislaine Moboula, Salima Hajjaji

Department of Pediatrics II, University Hospital for Mother and Children Abderrahim Harrouchi, Casablanca, Morocco

Abstract

Congenital heart disease (CHD) is synonymous with a frequent, serious, very long-lasting disease. It is necessary throughout the child's development phase and conditions his or her lifestyle. This is due on the one hand to the physical health problem, but also to the appearance of secondary psychological and social disorders, the possible course of the child's life conditions the quality of it, his future autonomy is therefore the total success of the treatment. The problems of the child and his or her family must be addressed in a comprehensive manner by the paediatrician and the attending physician, who must accompany them in facing the obstacles of society. The pediatric cardiologist and the attending physician must inform the parents of the diagnosis, although it is difficult, and endeavour to give all the required information and clear, precise recommendations, adapted to the specific situation of the child. In this work we report a prospective study on a series of 51 children and their parents over a period of 5 months in a hospital setting, while performing a bibliographic search in the main search engines and research in the field of psychology.

Keywords

Difficulty of the Diagnostic Announcement, Congenital Heart Disease, Psychology, Parent, Child

1. Introduction

Congenital heart disease (CHD) remains a major public health problem to this day. Thus, the Annunciation, which remains like a cataclysm in the eyes of the parents, causes several changes in their lives and involves a process of adaptation. The announcement of such a diagnosis is a difficult act for health professionals, especially in the face of the delay in diagnosis and therapeutic management. This is a very crucial step for both the patient and the caregiver and can have a big impact on how the disease is experienced afterwards. The diagnosis announcement, although difficult to formulate, the health professional must find all the ideal and adequate

methods for a good approach and better management.

2. Materials and Methods

We report a prospective study of a series of 51 children and their parents over a period of 5 months in a hospital setting, while conducting a bibliographic search in the main search engines and research in the field of psychology. The objective of our work was to evaluate the difficulty of this diagnosis announcement by the doctor to the parents.

^{*}Corresponding author: angelakibangou@gmail.com (Angela Kibangou)

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3. Results

51 cases were collected, including 28 boys and 23 girls. The sex ratio = 1.21, the mean age of our patients was 9.25 years with extremes of 1 month and 4 years, a peak for the age group between 6-12 months.

In our series, 40% of cases accepted the disease, which made it easier for doctors to regularly monitor their child, but more than half still pose a problem of surgical management, on the other hand 60% of cases were in total denial and despair, among which 2/3 of these children were lost to follow-up.

4. Discussion

The announcement of a diagnosis of a congenital disease is the most crucial moment; which remains so difficult for parents, because it implies for most of them a moment of mourning. This announcement remains so difficult for health professionals, most of whom feel pain, for the most part sadness and anger. It is all the more important to train and prepare healthcare professionals for this, as this affects not only patients, but also those around them.

The therapeutic relationship between the care team, the patient and his or her loved ones develops as soon as the diagnosis is announced. If this first step goes well, it can be a solid foundation for establishing a good and solid relationship later on. The way in which the diagnosis is announced has an impact on the emotions experienced, the attitude towards the disease, the trust in the medical team and the compliance with treatments and follow-up. Among the factors related to the interview in order to be able to establish a good diagnostic announcement, we find the physical setting, the people present, the information received and the way to do it, the ideal is to be able to plan any meeting in advance, it is all the more important to note that many doctors experience constraints to the quality of their interview, Hence the importance of good preparation. [1] The announcement in our context is made either by the doctor or by the senior, for parents with a particular profile the announcement must be done by the senior. During this stage of annunciation, the doctor must be patient, persuasive and find the ideal and adequate words in order to put the family at ease. Suffice to say that the formulation of the diagnosis is necessarily accompanied by a long and complex exchange on what the child's life will ultimately be, the importance of the quality of the first reception made by the doctor is very essential for a good diagnosis, the need to take time to receive the family is very capital, the doctor must keep the child at the center of the diagnostic announcement, Although the presence of a child with a health problem is, first and foremost, a considerable source of stress for parents [2, 4, 6, 9, 13, 14] and therefore causes various changes and many consequences on the personal, family and social levels. Among the means intended to help and inform parents of children with chronic illnesses, Discussion groups are partic-

ularly interesting, so the doctor must organize this kind of help group [11, 12]. In addition to the trauma of the diagnosis, the child's illness frequently leads to feelings of guilt in parents, which contributes to accentuating their anxiety. The first feeling of guilt lies in the fact that they were unable or able to protect their child from the disease. This feeling is even more intense when the disease involves genetic factors. The second feeling is that of feeling guilty towards their child, of not being able to realize the dream or desire they had developed for him. In our series, anxiety was the predominant element among parents with an impact on family life. The diagnosis of heart disease has a considerable impact on family life and can lead to serious difficulties, it is important to take into consideration the possibility of dramatizing on a daily basis, because due to the seriousness of the diagnosis several irrational anxieties can be concealed. All the writings emphasize the magnitude of the shock and the range of emotions (anger, fear, despair, helplessness, etc.) Which can arise in parents at the time of the announcement [3-5], as we have seen in our series. Despair and anger follow negation, which is when parents realize the child's true disability or deficiency. The problems caused by the presence of the child come to the fore, the parents pause for a thousand and questions, the anger that manifests itself during this stage towards oneself, towards the spouse, the child and towards the health professionals or those around them. Parents feel guilty and doubt themselves.

Being diagnosed with a chronic disease in a child can sometimes destabilize the entire family dynamic (5,8). This precipitates the whole family into an acute emotional crisis, triggered by the threat of losing the child and the questioning in fantasy of immortality, the serious illness threatens the bonds of attachment and impacts the child's basic security. According to the studies reviewed, parents' anxiety can be increased by: the adaptation requested and the mobilization of the resources necessary to cope with the situation [7, 8]. The seriousness of the child's condition; And a feeling of a battle already lost in the face of this new reality, this seriousness leads parents to impulsively strengthen the emotional ties with their children, in their concern for protection, they tend to isolate him, locking him up in a real fortress that prevents him from escaping to another place strewn with pitfalls. Parents also tend to isolate themselves [2, 5, 8]. The announcement of congenital heart disease is a thunderous cost that shakes the family, darkens the future, turns fatherhood into a nightmare and induces reactions that blur the understanding of the information that the doctor is trying to convey, the reactions are varied, unexpected and extremely complex. In general, parents are first looking for a way to escape from reality and have difficulty understanding or hearing what is being said, some seem to temporarily lose all contact with reality, for the most part flee in the vague hope of a medical miracle and refuse to recognize the identity of the child, desire his death or even consider placing him in an institution. In our series, we also noticed the fact that fathers isolated themselves and remained in denial of the disease.

Indeed, announcing this diagnosis to those around them would plunge them back into their emotions, especially since they are rarely prepared to notify their loved ones. Given the shock that parents receive; It is important to take into consideration their needs such as: need for normality, meaning and certainty and uncertainty; need for information; need for support; and the need for partnership. Gradually parents tend to develop more positive and subtle attitudes, for example for some want to understand the causes and origin of the disease and most often question their ability to manage this, in the end their emotions are very ambivalent, and for others may show aggression towards hospital staff.

Faced with all the disastrous situations they face, such as the threat of parents, aggressiveness during the diagnosis, health professionals must quickly develop a control of their emotions, in order to be able to provide the support they need. In order to provide adequate help, professionals must have reflected on the situation themselves and become aware of their own reaction, weakness and prejudice. They must understand the family dynamics and accept the different reactions of the parents and their intensities [10, 15]. In short, they must be able to assess situations and take appropriate action, respect the pace and maintain warm contact. They will be able to create a climate of trust, to establish relationships with the parents that allow for positive exchanges. This was to promote the optimal development of the child, while maintaining family harmony. However, for a better follow-up, and a good contact with the parents, a good correlation between the paediatrician and the psychologist is all the more important, given the risks that the child runs, a psychological preparation is therefore necessary, on the contrary when the diagnosis allows to predict a prolonged pathology, transforming the life of the child as well as that of the family into a sober tunnel, Psychological support for the family and the patient is desirable, the impact of the psychological effects can condition the therapeutic approach.

Finally, put in place measures to reassure their parents, to put a smile back on their faces and above all to make them responsible for the chronic pathology from which their child suffers.

5. Conclusions

The announcement of a congenital heart disease remains a difficult ordeal and represents a significant and painful experience. Few accept it and some remain in total denial, especially when it comes to long-term follow-up with an impact on their quality of life. Thus, in order to optimize the support offered to parents and to offer them both psychological and informative help, it is necessary that the medical profession considers the parental needs, remains attentive in order to reduce the rate of this diagnostic difficulty, finally despite all the constraints or difficulties encountered, the diagnostic announcement can be satisfactory both for the care team, that for the child and his parents, health professionals have a great challenge to meet, the awareness of the suffering of parents

and the ability of human beings to adapt can undoubtedly lead them to identify the words likely and adequate to help and reduce the distance that most often occurs between doctors and parents with congenital heart disease.

The situation of a child with congenital heart disease and their parent is particularly delicate and very complex, in this perspective we must be able to understand them; Reflect on our attitudes and behavior towards them, the diagnosis announcement although difficult, must be done as soon as possible in order to promote the development of the child and to be able to offer him the best chance to flourish, in addition to assisting the parents in their actions. Thus, different assistance services must be organized, so that parents can adapt to the reality encountered.

Abbreviations

CHD Congenital Heart Disease

Author Contributions

Soundousse Salimi: supervision, investigation, methodology; visualization, validation writing-Review et editing

Angela Kibangou: Funding, acquisition, methodology, project administration, validation, writing -review editing, writing original draft

Nisrine EL Marzouki: Methodology, supervision, validation

Christlaine Moboula: Methodology, funding, acquisition, validation

Salima Hajjaji: Methodology, supervision, validation

Conflicts of Interest

The authors declare no conflicts of interest.

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Research Fields

Soundousse Salimi: Cardiology pediatric
Angela Kibangou: General pediatric
Nisrine EL Marzouki: General pediatric
Christlaine Moboula: General pediatric
Salima hajjaji: General pediatric