









What is important in family counseling in cases of fetuses with congenital heart disease?

Marcela Bezerra Dias¹ , Luisa Tiemi Souza Tuda² , Luana Izabela Azevedo de Carvalho³ ,
Thayla Lais Estevam¹ , Bruno Mori⁴ , Ana Luiza Menezes Teles Novelletto¹ , Edward Araujo Júnior^{5,6*} ,
Luciane Alves da Rocha Amorim¹ 

INTRODUCTION

Fetal medicine has opened up new ways to examine, diagnose, and treat the fetus. The increased demand for fetal ultrasound has helped increase the number of congenital malformations diagnosed. Since congenital heart disease (CHD) is the most common fetal malformation¹ and considering the great evolution of congenital heart surgery worldwide, adequate therapeutic planning should be required with the goal of always reducing the risk of infant morbidity and mortality². Therefore, good counseling of these family members during the prenatal period is essential³ because this emotional support helps the parents make decisions that allow for better birth planning and more favorable neonatal care.

EMOTIONAL STATE OF PREGNANT WOMEN RECEIVING A FETAL DIAGNOSIS OF CONGENITAL HEART DISEASE

The prenatal diagnosis of a fetal anomaly is a traumatic event in the life of future parents, resulting in intense grief and psychological distress. Therefore, good counseling is important because this emotional support strengthens not only the doctor–patient relationship but also the trust between family members and health care professionals. This process provides security in the therapeutic management and guides the parents in making any decision, whether or not to interrupt the pregnancy, depending on the laws and sociocultural characteristics of the country^{4,5}.

Following the diagnosis, prospective parents express a need for ongoing support and information as they are concerned about the

future of this child⁶. Particularly at the first visit, the initial reactions of shock and sadness to an abnormal finding can inhibit the parents' ability to retain information, making the initial consultation challenging. It is necessary to explain potentially complex anatomical details to a family when stress levels are very high. Ideally, there will be an opportunity for follow-up appointments to adequately complete the counseling and to reinforce points that may have been missed in the midst of an emotional first encounter⁷.

However, such counseling is not free of difficulties and ethical dilemmas. This is mainly because we have to inform very distressed parents about the nature and consequences of CHD, early and late outcomes, possible complications at the time of delivery, the need or not for medical treatment, the timing of surgical or hemodynamic intervention, and the risks associated with each step of the procedures. Sometimes, the information obtained from the fetal examination is incomplete or refers to injuries that may evolve during the gestational period to improve or worsen the prognosis⁸. In addition, the information provided cannot take into account possible therapeutic advances that may occur in the future, as they may alter the quality of life and outcomes of affected individuals.

In view of the above, adequate family counseling should be considered a fundamental step in the management of CHD in the fetus, requiring health care professionals' skills and abilities beyond the confirmation of the heart disease and also including continuous monitoring that guarantees the welcoming and safe outcomes needed for each case. Therefore, specialists in fetal cardiology have an ethical obligation to keep their theoretical knowledge and practical skills up to date to ensure good counseling for these family members⁹.

¹Universidade Federal do Amazonas, Medical School, Postgraduate Program in Health Sciences – Manaus (AM), Brazil.

²Universidade Federal do Amazonas, Medical School, Medical Course – Manaus (AM), Brazil.

³Universidade do Estado do Amazonas, Medical School, Medical Course – Manaus (AM), Brazil.

⁴Universidade Federal do Amazonas, Institute of Health and Biotechnology – Manaus (AM), Brazil.

⁵Universidade Federal de São Paulo, Paulista School of Medicine, Department of Obstetrics – São Paulo (SP), Brazil.

⁶Universidade Municipal de São Caetano do Sul, Medical Course – São Caetano do Sul (SP), Brazil.

*Corresponding author: araujojed@terra.com.br

Conflicts of interest: the authors declare there is no conflicts of interest. Funding: none.

Received on January 08, 2023. Accepted on February 23, 2023.

IMPORTANCE OF FAMILY COUNSELING

Family counseling involves guiding fetal heart disease. It is therefore a complex skill that requires in-depth knowledge of normal cardiac physiology and CHD, treatment and prognosis data, communication skills, and emotional intelligence. It is pervasive in describing the heart disease, the child's expected course, typical outcomes, and genetic associations and communicating the most evidence-based data related to prenatal and postnatal outcomes¹⁰.

Studies show that family members who receive information about a fetal anomaly immediately have less understanding of the information and an inability to manage their feelings¹¹ and show more anxiety and depression compared to family members who receive the postnatal diagnosis¹². These characteristics emphasize the importance of family counseling from the detection of the first sign of alteration in the fetus, and it is also very important to consider the self-medication experience for the relief of anxiety and stress of these mothers¹², giving more time for family members to understand about heart disease and the necessary neonatal care. Some reports show an improvement in the bond between the pregnant woman and her partner, and between the parents and the child, with the awareness of their cardiological condition¹³.

Other members of the affected family may want to be involved in the decision-making process. In addition, health care professionals, with their sociocultural beliefs, may influence family members by taking into account the emotional burden

on the family, possible surgical procedures, future hospitalizations, the risk of complications, and the financial costs that the family may need during this period¹⁴. Therefore, care must be taken to ensure that counseling of these family members is done impartially by the welcoming team, as all of these factors can interfere with the free will of parents and family members¹⁴.

Prenatal counseling of families with CHD is one of the main tasks of fetal cardiologists or maternal-fetal medicine specialists after diagnosis¹⁵. However, we consider the need for the presence of other health care professionals in this emotional support, considering that we must holistically help these families, knowing that, in addition to the medical aspects, there are psychological and sociocultural conditions that must be addressed.

Lee⁷ presents important elements for prenatal counseling for these family members. She describes important topics for communicating information about the diagnosis of CHD, considering possible complications and necessary treatments. This model promotes a more assertive follow-up by presenting important aspects that should be part of the counseling of the pregnant woman. A proposed model of emotional support for pregnant women who receive a diagnosis of fetal heart disease is presented, taking into account the point of view defended by the authors with a multidisciplinary approach (Table 1).

The abovementioned elements help the professionals of the multidisciplinary team carry out family counseling, covering different dimensions of management, from the technical guidance on the disease to the basic and complex requirements

Table 1. Multidisciplinary counseling for family members diagnosed with congenital heart disease.

Medical aspects
<ol style="list-style-type: none"> 1) Medical explanation of the diagnosis. 2) Medical clarification on follow-up. 3) Medical clarification on the treatment. 4) Preparation for favorable and unfavorable outcomes in the case of evolution or termination of pregnancy. 5) Suggestion of preventive treatment for new pregnancies. 6) Medical clarification on the association with genetic alterations.
Psychological aspects
<ol style="list-style-type: none"> 1) Anamnesis and post-diagnosis reception. 2) Verification of the degree of understanding and adherence to the medical information suggested in the case. 3) Verify the psychic structure for the treatment and the experience of the outcomes of the case. 4) Emotional follow-up support for the pregnant woman and her family. 5) Clarification for the multidisciplinary team about the follow-up of the case.
Social aspects
<ol style="list-style-type: none"> 1) Provide written materials on the diagnosis and treatment of CHD. 2) Provide information about support groups. 3) Check family financial issues and psychological support. 4) In case of hospital discharge, check the medications, the possible need for home monitoring, and the outpatient follow-up of the pregnant woman. 5) In matters of long-term surgical interventions, consider cardiological follow-up in the other phases of life.

Adapted from Lee⁷.

that are expected to be promoted in facing the crisis situation: the essential emotional embrace. Therefore, it is necessary to appreciate the role of each professional, including doctors, psychologists, and social workers.

In view of the above, we would like to make a small reflection on the kind of advice we give to these family members: are we really welcoming these pregnant women?

We must consider that we are not facing an isolated problem, especially when we talk about parental relationships. Because when the mother makes this decision alone, whether without the father of the child or considering the extension of the family, for example, grandparents, aunts, uncles, and siblings, communication is fundamental and must be taken into account so that the decision is assertive, precise, and clear. In any case, opinions and positions must be taken into account, especially if one or more family members close to the parents concerned have a very strong opinion about how the pregnancy should proceed¹⁶.

PSYCHOLOGICAL AND SOCIAL ASPECTS OF FAMILY COUNSELING WITH FETAL DIAGNOSIS OF CONGENITAL HEART DISEASE

Psychological counseling is an intervention by a health care professional that differs from clinical intervention in certain aspects, such as it is situational in nature, it is focused on solving the subject's problems, it is an intervention focused on the present, it has a shorter duration, and it is more action-oriented than reflection-oriented. It consists of a helping relationship that aims to facilitate the subject's adaptation to the situation in which he finds himself by optimizing his personal resources, self-knowledge, self-help skills, and autonomy in facing his difficulties and problems¹⁷.

There are several theoretical perspectives of psychological counseling such as psychodynamic, humanistic, cognitive-behavioral, phenomenological-existential, feminist, constructivist, and systemic. The cognitive-behavioral perspective is the most recommended in the context of health and illness because it is the one that best fits the context and rhythm of health care.

Parents' cognitive activity after receiving the diagnosis can influence their behavior and emotions, which can lead to psychological disorders resulting from cognitive distortions, the way parents understand events and make them their central beliefs, which are not very adaptive and invariant to change.

Therefore, the cognitive-behavioral theory can help the patient adhere to the treatment by offering emotional support and improving quality of life¹⁸. In this way, the goal is to show that the influence on us is not directly the daily events and

situations, but the way we interpret each of these situations so that we can act consciously, elaborating feelings and emotions in the promotion of new behaviors within a broader view of the internal and external world.

Counseling for pregnant women who receive a fetal diagnosis of CHD can be conceptualized as the process by which affected parents go through a grief response with the familiar components of sadness, shock, denial or disbelief, anger, guilt or shame, and grief with a sense of being alone. There is also a desire, or "negotiation", for a delay with the miraculous loss of the problem, followed by eventual resolution and reconstruction¹⁶.

One of the first goals of the cognitive-behavioral approach in the process of accepting a diagnosis is to identify the patient's interpretations of their health-disease process in order to begin to restructure dysfunctional thoughts, adopting interpretations that are based on existing evidence in reality rather than considering irrational premises¹⁹.

Most cognitive therapists begin the client's treatment by identifying automatic thoughts and cognitive distortions in the face of a crisis and, in the long term, by examining intermediate beliefs. In this way, cognitive therapy demonstrates the importance of developing the patient's autonomy, which is achieved through the process of training the patient to have the skills to modify dysfunctional thoughts, behaviors, and/or emotions¹⁸.

The role of the therapist, at this point, is to help the patient think and act in a more realistic and adaptive way considering his psychological problems and, in this way, reduce the symptoms²⁰. Therefore, it is up to the psychologist to analyze the variables that interfere with the life of each patient in order to understand how these variables influence their behavior and feelings in the face of the new situation and possible illnesses such as depression and anxiety.

In clinical practice, we have observed social difficulties that should be considered important. The first observation is the language barrier: the lack of understanding of the cardiologic situation due to the lack of fluency in the foreign language, which requires the presence of an interpreter to help clarify the issue²¹. Another very important concern is to provide information about the disease in a didactic way, using drawings, templates, or reliable information websites²¹. Professionals must avoid using confusing medical terms, as many family members, especially those with less education, have difficulty understanding CHD²². Contact with other family members with similar diagnoses can provide emotional support during the stages of this process. Family situations such as lack of emotional or financial support can make it difficult for this pregnant woman to progress to more appropriate treatment, for example, when there is a need for transfer. The cultural and

religious aspects can help with the acceptance of the fetus with heart disease²³. There are countless social conditions that can influence this decision-making process, so there is also a need for good social support.

We suggest that family counseling in these cases of fetal diagnosis of CHD should follow a biopsychosocial approach, that is, it should consider health status, psychological well-being, and social skills, promoting the combination of specialized psychosocial intervention with medical intervention²⁴. The history of the pregnant woman, her environmental conditions, personal experiences, and religious and financial aspects must be taken into account, as they are questions to be therapeutically elaborated, the source of which will present the solution to promote the psychic and emotional balance of coping with the demand now manifested, in this case, the heart disease of the child.

CONCLUSION

Counseling family members who receive a diagnosis of congenital heart disease during pregnancy is complex, mainly because

of the positive focus on health rather than disease. In this regard, we support the idea that a multidisciplinary team is necessary for good counseling, as we must be able to meet the medical, psychological, and social needs of these individuals. It is also worth mentioning that it is important to evaluate the way this counseling is done and to observe its results, understanding that this is a contemporary issue and that we have a learning curve to develop.

AUTHORS' CONTRIBUTIONS

MBD: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology. **LTST:** Formal Analysis, Investigation, Methodology, Writing – original draft. **LIAC:** Formal Analysis, Investigation, Methodology, Writing – original draft. **TLE:** Conceptualization, Data curation, Formal Analysis, Investigation, Methodology. **BM:** Investigation, Methodology. **ALMTN:** Conceptualization, Data curation, Formal Analysis, Investigation, Methodology. **EAJ:** Validation, Visualization. **LARA:** Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing.

REFERENCES

1. Donofrio MT, Moon-Grady AJ, Hornberger LK, Copel JA, Sklansky MS, Abuhamad A, et al. Diagnosis and treatment of fetal cardiac disease: a scientific statement from the American Heart Association. *Circulation*. 2014;129(21):2183-42. <https://doi.org/10.1161/01.cir.0000437597.44550.5d>
2. Regitz-Zagrosek V, Roos-Hesselink JW, Bauersachs J, Blomström-Lundqvist C, Cifková R, Bonis M, et al. 2018 ESC guidelines for the management of cardiovascular diseases during pregnancy. *Eur Heart J*. 2018;39(34):3165-241. <https://doi.org/10.1093/eurheartj/ehy340>
3. Gedikbaşı A, Oztarhan K, Yıldırım G, Gül A, Ceylan Y. Counseling and outcomes of antenatally diagnosed congenital heart anomalies in Turkey. *Anadolu Kardiyol Derg*. 2011;11(2):137-45. <https://doi.org/10.5152/akd.2011.035>
4. Sandelowski M, Barroso J. The travesty of choosing after positive prenatal diagnosis. *J Obstet Gynecol Neonatal Nurs*. 2005;34(3):307-18. <https://doi.org/10.1177/0884217505276291>
5. Carlsson T, Mattsson E. Emotional and cognitive experiences during the time of diagnosis and decision-making following a prenatal diagnosis: a qualitative study of males presented with congenital heart defect in the fetus carried by their pregnant partner. *BMC Pregnancy Childbirth*. 2018;18(1):26. <https://doi.org/10.1186/s12884-017-1607-y>
6. Bratt EL, Järholm S, Ekman-Joelsson BM, Mattsson LÅ, Mellander M. Parent's experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease--a qualitative study in a Swedish context. *BMC Pregnancy Childbirth*. 2015;15:171. <https://doi.org/10.1186/s12884-015-0610-4>
7. Lee CK. Prenatal counseling of fetal congenital heart disease. *Curr Treat Options Cardiovasc Med*. 2017;19(1):5. <https://doi.org/10.1007/s11936-017-0502-1>
8. Menahem S. Ethical questions arising from counselling in fetal complex congenital heart disease. *Monash Bioeth Rev*. 2012;30(2):62-7. <https://doi.org/10.1007/BF03351340>
9. Howe D. Ethics of prenatal ultrasound. *Best Pract Res Clin Obstet Gynaecol*. 2014;28(3):443-51. <https://doi.org/10.1016/j.bpobgyn.2013.10.005>
10. Keelan JA, Moon Grady AJ, Arya B, Donofrio MT, Schidlow DN, Tacy TA, et al. Current state of fetal heart disease counseling and training: room for improvement?: endorsed by the fetal heart society. *Pediatr Cardiol*. 2022;43(7):1548-558. <https://doi.org/10.1007/s00246-022-02882-4>
11. Bratt EL, Järholm S, Ekman-Joelsson BM, Johannsmeyer A, Carlsson SÅ, Mattsson LÅ, et al. Parental reactions, distress, and sense of coherence after prenatal versus postnatal diagnosis of complex congenital heart disease. *Cardiol Young*. 2019;29(11):1328-334. <https://doi.org/10.1017/S1047951119001781>
12. Zhu M, Liang H, Feng J, Wang Z, Wang W, Zhou Y. Effectiveness of medical self-experience counseling in pregnant women after echocardiographic detection of a suspected fetal heart anomaly: a longitudinal study. *J Obstet Gynaecol Res*. 2016;42(10):1236-44. <https://doi.org/10.1111/jog.13050>
13. Sklansky M, Tang A, Levy D, Grossfeld P, Kashani I, Shaughnessy R, et al. Maternal psychological impact of fetal echocardiography. *J Am Soc Echocardiogr*. 2002;15(2):159-66. <https://doi.org/10.1067/mje.2002.116310>
14. Rempel GR, Cender LM, Lynam MJ, Sandor GG, Farquharson D. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *J Obstet Gynecol Neonatal Nurs*. 2004;33(1):64-70. <https://doi.org/10.1177/0884217503261092>
15. Kovacevic A, Elsässer M, Fluhr H, Müller A, Starystach S, Bär S, et al. Counseling for fetal heart disease-current standards and best practice. *Transl Pediatr*. 2021;10(8):2225-34. <https://doi.org/10.21037/tp-20-181>

16. Menahem S, Grimwade J. Pre-natal counselling--helping couples make decisions following the diagnosis of severe heart disease. *Early Hum Dev.* 2005;81(7):601-7. <https://doi.org/10.1016/j.earlhumdev.2005.02.001>
17. Trindade I, Teixeira JAC. Aconselhamento psicológico em contextos de saúde e doença - intervenção privilegiada em psicologia da saúde. *Análise Psicológica.* 2000;1(XVIII):3-14. <https://doi.org/10.14417/ap.418>
18. Sousa ME, Scherer AA, Ramos FL, Baião VB. The hospitalized patient in the light of the theory cognitive-behavioral. *Psicol hosp. (São Paulo).* 2015;13(1):19-41.
19. Pereira FM, Penido MA. Theoretical practice applicability of cognitive behavior therapy in hospital psychology. *Rev Bras Ter Cogn.* 2010;6(2):189-220.
20. Powell VB, Abreu N, Reis Oliveira I, Sudak D. Cognitive-behavioral therapy for depression. *Rev Bras Psiquiatr.* 2008; 30(Suppl 2):73-80.
21. Carlsson T, Marttala UM, Mattsson E, Ringnér A. Experiences and preferences of care among Swedish immigrants following a prenatal diagnosis of congenital heart defect in the fetus: a qualitative interview study. *BMC Pregnancy Childbirth.* 2016;16(1):130. <https://doi.org/10.1186/s12884-016-0912-1>
22. Kovacevic A, Wacker-Gussmann A, Bär S, Elsässer M, Mohammadi Motlagh A, Ostermayer E, et al. Parents' perspectives on counseling for fetal heart disease: what matters most? *J Clin Med.* 2022;11(1):278. <https://doi.org/10.3390/jcm11010278>
23. Im YM, Yun TJ, Yoo IY, Kim S, Jin J, Kim S. The pregnancy experience of Korean mothers with a prenatal fetal diagnosis of congenital heart disease. *BMC Pregnancy Childbirth.* 2018;18(1):467. <https://doi.org/10.1186/s12884-018-2117-2>
24. Scott MJ, Dryden W. The cognitive-behavioural paradigm. In: *Handbook of counselling psychology.* Thousand Oaks, CA, USA: Sage Publications, Inc; 1996.p. 156-79.

