
Role of Counseling in Fetal Congenital Heart Diseases

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Counseling is a profession that helps individual, family, or group through the relationship between the professional and client. Counseling facilitates the processes of change and improves the quality of life, enhancing both the resources and the relationships with the environment surrounding. The fetal echocardiography is a technique born in the late 1980s, when the improvement of ultrasound technology has made it possible to highlight the characteristics of the fetal heart. Huhta JC, one of the fathers of this method, wondered immediately if, without the possibility of dealing with in utero congenital heart disease, it was useful or advisable to diagnose before birth. Numerous studies have now clearly demonstrated that a team consisting of a gynaecologist and a cardiologist pediatrician can diagnose with very high accuracy a number of congenital heart defects in the fetal stage; so, the spectrum of the anomalies discovered in the uterus is almost superimposed on the heart disease observed at birth. Nowadays, high attention to the anatomy of the fetal heart is associated with an equally close attention to the psychological aspect of the matter: in practice it is not always possible to deal adequately with the counseling prospective parents.

In the last years, thanks to the ultrasound equipment and to the skills of the perinatologists, the prenatal diagnosis of fetal malformation is improved, and it's now possible to detect or suspect a fetal malformation from the mid-gestation. This is for sure an important improvement in the field of the fetal medicine, but it resulted in another issue, the ones related to the counseling, the ethical and psychological aspect of the problem. These aspects are of great important as we can see by the large and growing scientific literature on this argument [1–4]. As a consequence of

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these observations, many authors [5, 6] state that it is mandatory a multidisciplinary counseling comprise the obstetrician, the cardiologist, the pediatric surgeon, and the psychologist, in order to provide a comprehensive information to the parents. This raises the question of whether or not repeated consultations during the follow-up of the mother and the fetus, on the one hand, could improve the emotional side of parents, but according to others, this approach would worsen the anxiety. At present the literature did not arrive at conclusions supported by evidence [7, 8]. There is evidence that prospective parents may be able to face up with anxiety with a psychological support; therefore, in these cases a single consultation may be inadequate.

4.1 Invasive Fetal Cardiac Intervention (FCI)

The outcome of fetuses with congenital heart disease, developing a postnatal univentricular heart despite improvements in neonatal surgical care and development of dedicated follow-up programs, remains poor. This case has become the main indication for antenatal intervention. Postnatal surgery, which results in a far from optimal single-ventricle Fontan-type circulation [9], has a considerable mortality rate, leading to a total long-term survival of less than 65 % [10]. Numerous studies have been published documenting the natural history of congenital heart defects in utero and the potential of prenatal progression [11, 12]. A well-functioning biventricular heart may develop into a univentricular heart, or it may acquire myocardial damage, which can lead to congestive heart failure, arrhythmias, hydrops, and intrauterine death. Pulmonary development may be also affected. It would therefore seem logical that a fetal intracardiac intervention at the right time and in the right fetus should be able to improve or even normalize hemodynamics and to prevent secondary damage to the fetal heart and lungs [13]. Recently, technological advances in fetal cardiac imaging have given us a window into the womb, creating the field of fetal cardiology, where the fetus is considered an individual patient from the time of diagnosis. One of the challenges we face as fetal caregivers is that we must strive to understand the “prequel” of what we already know: the natural history and progression of congenital heart disease in utero. More than 25 years ago, researchers reported that structural heart disease, specifically aortic stenosis, evolves in utero [11]. Fetal therapy, either by catheter intervention or surgery, is based on the fundamental principle that intervention will alter the natural history of the disease process. To prove that this is true, we must first gain an understanding of the unaltered progression of heart disease in utero. Referral centers have shown that fetal cardiac intervention can be performed successfully, with minimal risk to the mother and encouraging outcomes for fetuses, particularly in those with aortic stenoses evolving to HLHS hypoplastic left heart syndrome (HLHS).

4.2 Counseling in Fetal Cardiac Intervention

In recent years, several advances have been made in the fetal cardiac intervention of congenital heart disease. All these advances are accompanied by the need to be prepared for the best to be able to explain clearly to parents what are these

procedures and the risks associated with them. Indeed counseling with parents regarding these procedures really becomes a very delicate process. It must not only be accurate in the technical description of the procedure, but list all of the risks and complications and less common and finally also understand the emotional side. Counseling is both multidisciplinary and multistage. Of primary importance is the story of the mother, the presence of diseases and allergies, or taking drugs. A careful consultation should be carried out with the consultant physicians. The counseling should be carried out in the presence of both parents and possibly all members of the family who may support the decision.

The duration varies from case to case; it is necessary to be sure that parents have understood all the risks associated with the procedure and all the possible complications postprocedure. Only after being sure that counseling has been comprehensive, you may ask the parents to sign written informed consent. If it is assumed that the parents do not demonstrate a clear understanding of the benefits and risks of the procedure, it is a contraindication to the same.

Parents are counseled extensively about the maternal and fetal risks.

4.2.1 Maternal Risk

The mother's safety, health, and future reproductive potential remain the priorities when undertaking fetal therapy. A comprehensive preprocedure workup is performed to exclude maternal contraindications for the procedure. Nevertheless, complications related to the anesthesia, laparotomy, and uterine manipulation can occur. In addition, a sick or hydropic fetus can lead to premature labor or the maternal mirror syndrome, a preeclampsia-like syndrome for which the only therapy is the delivery of the sick fetus. Given appropriate technique, maternal morbidity is rare, except when uterine exposure is needed or when fetal deterioration requires immediate abdominal delivery [14]. The interventions remain invasive, as the amniotic cavity has to be entered transabdominally with an 18- or 19-gauge needle; there are inevitable risks for the mother such as prelabour preterm rupture of the membranes, premature labor, placental abruption, bleeding, or infection. The quoted pPROM rates 2–7% [15, 16]. Long-term outcomes are not yet available. The precise number of procedures and types of personnel needed for a successful center has yet to be determined, but analysis of registry data, including that in the International Fetal Cardiac Intervention Registry (IFCIR), may help us gain insight into the learning curve and the minimum number of cases needed to obtain initial, and maintain ongoing, proficiency.

4.2.2 Fetal Risk

Fetal death during the procedure is not uncommon (11%) and occurred across all procedure types. Additionally, early postprocedural (<48 h) fetal demise was an issue in this dataset. These rates, which are higher than those previously published in single-center experiences with fetal cardiac surgery, likely represent a

combination of different learning curves combined with the known complications of any invasive intervention in a compromised fetus [17]. Fetal intraprocedural complication rates remain high, with bradycardia and hemopericardium occurring in a significant number of cases and across all procedure types, underlining the need for a team of experienced maternal/fetal and pediatric cardiologist and surgical practitioners whenever these cases are performed. Fetal bradycardia is common, occurring in about 50% of cases in which there was needle access to a ventricle. Fetal bradycardia has not been experienced with access to the right atrium. The bradycardia is treated by discontinuing manipulation and either intramuscular or direct intracardiac administration of epinephrine. Small pericardial effusions are common, and moderate to large ones can occur and can be drained successfully. Thrombus formation within a ventricle can occur but usually resolves within days without treatment. Fetal aortic valve dilation may leave significant aortic regurgitation, which usually is well tolerated and improves or even disappears until the term. The rate of complications is definitely dependent on the experience of the operating team: fetal positioning, imaging, choice of the right instruments, correct diameter of the balloon, technique of balloon withdrawal, and management of complications have an impact and are subject to a learning curve [18].

Conclusions

During pregnancy there is a tendency to idealization of the unborn and attributed qualities, feelings, and abilities that he would like to possess. The child already has a fantastic space. The birth of a child with a birth defect is the loss of the imagined child. The new parents have to put together new indications. Considering that most of the diagnoses of fetal congenital heart disease are made after the 18th week of gestation, when the mother has already warned the first fetal movements. For these reasons gynaecologist and pediatric fetal cardiologist must have counseling skills, and a psychological support should be provided to the couple. The prognosis is a communicative event and not only an informative event. To follow the patient through difficult choices is one aspect of the medical profession as important as the diagnostic and therapeutic competence. Building and maintaining a relationship require a prerequisite: the empathy which is the imaginary reconstruction of the experience of the other. The counseling skills can be summarized in being able to maintain “the right distance” from the couple. It is important to learn to recognize our emotions and not to minimize the couple’s emotions. On the other hand, it is mandatory to avoid behavior of fusion like excessive familiarity with the couple.

In conclusion, it is necessary that those involved in counseling of the interventional procedures (cardiologists, gynaecologist, anesthesiologists, and parents) speak “the same language,” both in technical terms (avoiding language too complex) and, above all, in psychological terms. The needs of the couple must be put in the first place, and the pair is ridden without constraints in the difficult path that leads to the taking care of a fetus with a congenital heart disease. The words of Jean-Claude Fouron “We cannot run the Fetal echocardiography ignoring the consequences of our act” [19] enclosed all the complexity of this matter.

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