



Prenatal counselling and the role of the paediatric surgeon



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ABSTRACT

With the development of prenatal ultrasound and of foetal medicine, the paediatric surgeon has extended his knowledge of the natural history of surgical malformations. He is a part of the prenatal team and parents should always be referred to him when a surgical malformation is suspected, even when termination of pregnancy is planned because of an expected poor prognosis. Direct contact between the prenatal medicine specialist and the paediatric surgeon is also highly recommended to ensure continuity in the messages delivered to the parents. Postnatal counselling does not compare with prenatal counselling, and the paediatric surgeon has learned from the obstetrician to modulate his talk by including other conditions that might affect the outcome of the foetus, especially genetically determined syndromes. When the foetal malformation is diagnosed very early, especially in the first trimester, it therefore seems important for the consultation with the paediatric surgeon to be scheduled when the complementary exams required by the anomalies diagnosed are done, in order to avoid later contradictory messages. Repeated consultations should be favoured as they allow provision of more precise information regarding changes in ultrasound and/or MRI images and so decrease parents' anxiety and help them to take their decision. Foetal surgery, which has reached various stages of development in different countries, requires paediatric surgeons and obstetricians to join forces to optimise procedures and evaluate their benefit/risk ratio. Since 2004, the National Rare Disease Plan in France has allowed the creation of Rare Disease Centres, which deal with congenital malformations and produce recommendations for the health care pathway of these patients by means of a multidisciplinary approach. This greatly enhances interdisciplinary communication and ensures that best care is provided to the parents-to-be and to their child.

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Introduction

In the 1980s, paediatric surgery entered a new era with the beginning of foetal medicine. The foetus, until then simply ignored by the paediatric surgeon, became a potential patient. Obstetricians and paediatric surgeons thus progressively learned to work together for the sake of the expectant mother and her future child.

Ultrasound screening for foetal anomalies has become mandatory in most developed countries and in France, for example, 98% of pregnant women currently have access to prenatal ultrasound.¹ This has allowed the diagnosis of most foetal malformations and the concepts of natural history and hidden mortality have emerged.² Appropriate counselling of the parents-to-be includes foetal karyotyping when needed, level 3 ultrasound and/or MRI, precise prognostic evaluation, appropriate counselling with a

paediatrician or a neonatologist or a paediatric surgeon or a geneticist or a combination thereof and optimal organisation of the delivery, i.e., at the right time in the right place. In some cases, medical termination of the pregnancy may be discussed. Notwithstanding, the prognosis of many anomalies remains difficult to establish and 30–40% of malformations are still undiagnosed prenatally. The provision of appropriate counselling thus implies that the obstetrician is aware of the postnatal outcome of surgically repaired malformations and conversely paediatric surgeons have to know about the natural prenatal history of foetal malformations.

The obstetrician's point of view

Postnatal counselling does not compare with prenatal counselling, especially in early pregnancy. People are not dealing with a real child but with a child to be. In countries where termination of pregnancy is allowed, announcing a poor or uncertain prognosis

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for a foetal malformation could lead parents to choose termination. The main concern of the prenatal team is therefore to provide sufficient information to allow the parents to make an informed decision and to respect and protect parental autonomy.³ It has been shown that cognitive mechanisms that are elicited by emotions and which are not necessarily rational can have an important and beneficial function in parental decision making after ultrasound diagnosis of a foetal abnormality. Consequently, the process of parental decision making should not be assessed solely on the basis of its rationality, but also on the basis of the parental emotional outcome.⁴ Experience is required when making the extremely difficult decision of how much detailed information to give to the parents. The use of the Internet by most couples has to be taken into account and has certainly modified prenatal counselling over the last 10 years. Parents generally use the time between the first consultation, where the malformation has been suspected, and the consultation with the foetal medicine specialist to search for information on the Internet. Their understanding of the information they retrieve may vary greatly depending on the quality of the websites explored, the family story, and their cultural and intellectual background. The role of the foetal medicine specialist is first to delineate what the parents have correctly understood and to correct potential misinterpretations. The words used by the doctor or sonographer who announces the diagnosis are tremendously important. For example, if a diagnosis of abnormal genitalia is made, the words “hermaphroditism” and “ambiguous genitalia” will create major parental distress. In such cases, it is important that the patients first see the foetal medicine specialist in order to discuss the diagnosis and its implications. Another important issue is the medical team's ability to tailor the consultation to the family's information needs and knowledge base⁵ and to provide pictures of malformations that will be visible at birth.

From the obstetrician's point of view, communication with the surgeons has increased our knowledge of congenital malformations and improved our understanding of the surgeon's expectations on the basis of our ultrasound images. For example, we have learnt that it is important for prenatal counselling to measure the size of the defect in oesophageal atresia in numbers of vertebrae (when technically possible)⁶ and to describe the size of the diaphragm defect or the appearance of the corpus cavernosum in hypospadias.

The paediatric surgeon's point of view

Although numerous studies have demonstrated that counselling by the paediatric surgeon helps parents in their choice and acceptance of the disease, the channels through which paediatric surgical advice is given are not clearly defined and most current guidelines only deal with referral for genetic and neurological anomalies.^{7,8} A recent nationwide study in Italy on referral of parents to the paediatric surgeon found that although in 80% of cases the foetal medicine specialist advised parents to contact the paediatric surgeon, only 10 out of 38 centres took the initiative to make an appointment for the parents.⁹ Direct contact between the foetal medicine specialist and the paediatric surgeon before the referral is highly recommended, so as to avoid unnecessary additional anxiety about the timing of the surgical consultation for the parents and to exchange information about the previous consultation in order to prepare the next. The words used by the foetal medicine specialist to describe the suspected or confirmed malformation are critical. If incorrect or inconsistent with the paediatric surgeon's point of view and experience, these words will be difficult or even impossible to erase from the parents' memories and will condition how they will face up to the medical and

surgical procedures that their baby will have to undergo. This may also have an impact on the overall acceptance of the potential sequelae associated with the malformation. Although time consuming, the best solution—as in many fields—is a joint consultation with the obstetrician and paediatric surgeon, as reported by Patel et al.¹⁰ This should be particularly encouraged at the beginning of the case, to build common experience to strengthen team unity.

How do parents perceive the paediatric surgeon?

The obstetrician is the first to tell the parents about a foetal malformation: the bringer of bad news. He or she will explain the prognosis and likely outcome, but will not be the one who will take care of the baby after birth. The parents feel more trusting when discussing with the doctor who will try to correct the malformation and who will follow up their child long term, until adolescence or even beyond. This helps parents to project themselves into the future and to reduce their anxiety. Counselling with the paediatric surgeon is therefore mandatory for optimal prenatal care.

If any unplanned event occurs during the course of pregnancy, such as a change in the ultrasound appearance of the bowel in gastroschisis, a new appointment with the surgeon should be offered to the parents. Aite et al.¹¹ have reported a negative correlation between the number of antenatal consultations and the level of parental anxiety at birth. Parents who had at least two consultations (multidisciplinary counselling) showed significantly less anxiety at the birth of their child. Parents who know where their baby will be and who will take care of him or her also often like to visit the paediatric surgery department and neonatal intensive care unit and to meet with the neonatologist.⁵

The role of the multidisciplinary team

Decisions regarding antenatal follow-up, the timing, place and mode of delivery, as well as the procedures to be performed during the neonatal period should be discussed by the medical team prior to consultation with the parents. In 1996, Crombleholme et al.¹² reported that antenatal surgical consultation changed the site of delivery in 37% of cases, the mode of delivery in 6.8%, reversed the decision to terminate in 3.6% and influenced the timing of delivery in 4.5%. Nearly 20 years later, we feel that this should no longer be the case. Whether counselling is performed jointly or not, the medical team should be in perfect agreement regarding the decision that is taken. Receiving conflicting information from physicians increases parental anxiety and erodes confidence.⁵

To what extent should we counsel the parents?

The paediatric surgeon mainly relies on the information delivered by the foetal medicine specialist through ultrasound and/or MRI images. He or she is unable to examine the future patient, but is supposed to give information about the severity of the malformation, the possible surgical repair, the expected morbidity and the potential complications, including death in severe cases. This task should be sustained by good knowledge of the natural history and prognosis of the prenatal condition, which may differ from the same condition diagnosed postnatally. The information provided should also include other conditions that might affect the outcome of the foetus, especially genetically determined syndromes that alter the prognosis.

Should any possible complication be explained to the parents? For example, should prenatal counselling regarding a foetus with gastroschisis include mention of the rare occurrence of bowel

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