Fetal Surgery: Principles, Indications, and Evidence

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(Obstet Gynecol 2014;124:817-35)

Question 1:

What are the risks of intrauterine adhesions after “open” fetal procedures? Has there been any follow-up showing how these patients do in subsequent pregnancies? Is there any evidence of issues with abnormal placentation such as placenta accreta?

Response from Dr. Wenstrom and Dr. Carr:

A few follow-up studies have been done at the centers with the longest history of performing “open” fetal surgeries, and these indicate that there is an increased risk of uterine dehiscence, uterine rupture, and placenta accreta, requiring cesarean hysterectomy in subsequent pregnancies. One of the largest studies reported a 14% risk of uterine dehiscence and a 14% risk of uterine rupture in pregnancies following open fetal surgeries (see Wilson et al, Am J Obstet Gynecol 2010;203:209.e1–6).

Question 2:

Given how accepted fetal transfusion is as a therapy, how do you handle situations in which the parents have religious objections to transfusion?

Response from Dr. Wenstrom and Dr. Carr:

We have not encountered this in the many years over which we have offered this life-saving service, so we cannot answer from experience. However, if the parents objected to fetal transfusion on the same grounds as they would decline transfusion for themselves, we would, of course, honor their wishes. For adults, there are alternatives that help mitigate anemia experienced as a result of blood loss (iron infusions, intravenous fluids other than blood, etc) but, we do not have those alternatives for the fetus. With fetal anemia we have no alternative other than blood, and if that is not acceptable to the parents, then all we could offer is expectant management in accordance with the parents’ wishes. We would also encourage the parents to consult with their church elders to discuss the medical situation, our recommendation, and possible options.
Question 3:

Given the prevalence of twin-twin transfusion syndrome (9–15%) in monochorionic twins, how do you recommend monochorionic-diamniotic twins be followed to identify twin-twin transfusion syndrome early?

Response from Dr. Wenstrom and Dr. Carr:

There is a broad consensus in the literature and among practitioners that ultrasound exams every 2 weeks, beginning at 14 weeks, is reasonable. If there are any sonographic signs of progression, the interval between exams can be shortened to weekly or even twice weekly if needed. Part of the counseling we offer every patient is that progression is unpredictable, and that fetal demise is possible even when exams are performed at close intervals.

Question 4:

Since the overall benefits of many of these procedures are unknown, are these procedures covered by insurance?

Response from Dr. Wenstrom and Dr. Carr:

Fetal blood transfusion and shunt placement are considered standard of care and most insurance companies cover them. Laser ablation for severe twin-twin transfusion syndrome is also no longer considered an experimental procedure. That does not mean that all carriers pay for it; but, if they decline payment it is not because it is experimental. Most other procedures wherein benefit may be uncertain (most notably tracheal occlusion for congenital diaphragmatic hernia) are definitely considered experimental, and we negotiate with insurance carriers on an individual basis for each and every case. Our hospital has graciously waived fees in some cases where benefit seemed likely and the insurance carrier would not cover the costs, and other large hospitals may do the same in the best interest of their patients.

Question 5:

Given the high risk of preterm delivery, is there any role for maintenance tocolytics?

Response from Dr. Wenstrom and Dr. Carr:

If there was a tocolytic proven to prevent preterm delivery, it would be a great idea for patients who have undergone fetal surgery, since that is the most common adverse outcome after such procedures. Unfortunately, no such tocolytic exists. This is not surprising, since these kinds of fetal therapies likely instigate preterm labor by a variety of pathways (for example, bleeding, inflammation, thrombosis, and infection), and there is currently no tocolytic proven to interrupt even one of these paths. Additionally, the complications associated with long-term tocolytic use have been well documented. For these reasons we do not recommend long-term tocolytic use after invasive fetal therapies.

Question 6:

Given the importance of supporting families through this process, what do we know about how parents make the decision to undergo antenatal procedures? Are there special counseling principles that should be employed?

Response from Dr. Wenstrom and Dr. Carr:

Fetal surgery is fraught with morally complex issues, made more difficult by the fact that parents are usually learning for the first time about a complicated medical problem while they are dealing with an onslaught of
emotions such as disappointment, anger, guilt, hopelessness, and lack of control. The counseling issues involved are too complex to discuss in a paragraph; but, most fetal surgery programs use a multidisciplinary approach to counsel parents about the fetal problem, the options, the risks, and the potential (but sometimes unproven) benefits, and many require a “reflective” period afterwards so that parents have the time to ruminate about all these issues with no pressure to make a decision. Perhaps the most important component is providing psychosocial support (social worker, genetic counselor, psychologist), and many centers also involve a medical

Question 7:

Is the fetus paralyzed when ablating urethral obstructions via fetal cystoscopy? If so, how is this accomplished and how is the fetus monitored during that time?

Response from Dr. Wenstrom and Dr. Carr:

Centers that perform fetal cystoscopy typically use a combination of fentanyl and a paralyzing agent such as pancuronium that is injected directly into the fetus.

Question 8:

What do you recommend for a general practitioner who has a patient that is newly diagnosed with a condition that may benefit from fetal surgery? Is there a national database that can be accessed to help determine which centers are performing some of these procedures and their entry criteria and outcomes? Could this be a good place for telemedicine?

Response from Dr. Wenstrom and Dr. Carr:

A national database would be a fantastic idea. The National Institutes of Health of course has a database that lists ongoing research trials; but, to our knowledge there is no database listing clinical centers that do nonexperimental procedures such as laser ablation for twin-twin transfusion syndrome. In most cases, the prenatal diagnosis is made by a maternal-fetal medicine specialist, who can then provide some guidance about what treatments are available and which centers offer them. The generalist who suspects a fetal anomaly and does not have a maternal-fetal medicine colleague in their geographic area could start by referring their patient to a hospital with a prenatal diagnosis center.