

# **Fetal Surgery and Right of Refusal**

**By Randy Horton, 2005**

Fetal Surgery is a recent medical intervention that involves operating on the fetus within the womb of the mother in order to prevent congenial birth defects and in many cases fetal death. This type of procedure generates numerous ethical considerations for both the medical establishment and the clients they serve. In particular one must consider that this type of procedure involves two patients.

Before fetal surgery medical interventions (for the most part) were focused on a single patient. The patient would usually make the decision to go through with the procedure or not. With the advent of fetal-surgery however the moral considerations become more complicated as any operation performed upon the fetus is also an operation performed on the mother. The moral and ethical considerations include the rights of the fetus and the rights of the mother.

In at least some cases where fetal-surgery could be a viable treatment there are morally justifiable reasons for the mother to refuse such treatment. These considerations include situations where there is significant risk to the life of the mother, situations where the benefit of the treatment is not clear, and situations which have not ruled out abortion of the fetus. In any of these cases the mother's right to refuse the treatment can be morally justified.

The medical establishment has its own initiatives to determine a moral and ethical framework for procedures involving fetal surgery which include research, diagnosis and treatments of fetal abnormalities. Parents however usually do not consider their moral or ethical stance on the subject unless they become placed in a situation which demands that they make a decision.

Before we move too far ahead, it is important to understand how one may arrive at this ethical crossroad. Without some kind of pre-natal diagnosis, there can be no determination which could lead to fetal-surgery. In this regard a client must first agree to a pre-natal diagnosis, followed by a determination as to whether fetal surgery is an option rather than abortion. For the purposes of this discussion we will focus on the option of fetal-surgery as a treatment and the option of abortion being refused by the mother.

There is no moral conflict in cases where the mother accepts the fetal surgery recommendation. However in cases where the mother refuses fetal-surgery as a treatment option the moral rights of the unborn child are often pitted against the moral rights of the mother.

In cases where fetal-surgery can treat an abnormality or prevent fetal-death and where there is no significant risk to the mother fetal surgery may be recommended. Two well documented fetal abnormalities which demonstrate low and high risk scenarios include “spinal bifida” and “congenial diaphragmatic hernia”.

“Spinal Bifida”, is a birth defect involving the deformation of the developing spinal chord. When the spinal chord develops normally, it starts out as a jelly like substance in which the spine forms around, followed by the flesh and skin of the fetus. In cases of spinal bifida, the spine and flesh do not fully form around the spinal fluid, leaving crystalline deposits on the outside of the fetus. This abnormality rarely causes death but if left untreated causes disabilities and a decreased quality of life within the new born child. It is not treatable post-birth as much of the deformation occurs during fetal development. The procedure to treat Spinal Bifida is un-intrusive and considered to be low-risk to the mother.

The second example is of higher risk and considered to be experimental. Congenial Diaphragmatic Hernia (CDH), affects <sup>1</sup>“1 in every 2500 babies... ..The cause is not yet known. 50% of these babies do not survive.” CDH happens when the fetus’ diaphragm doesn’t properly develop and organs move up into the chest cavity preventing the development of the lungs and heart. The fetal-surgery procedure for CDH involves inserting a balloon like object into the trachea of the fetus in order to secure space for the evolution of the lungs and heart. The balloon is then removed after birth.

Both of the above conditions have been successfully identified and treated through pre-natal diagnosis and fetal surgery. We can agree that the medical establishment has an obligation to only recommend fetal-surgery if it has the potential to improve the future quality of life for the fetus.

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<sup>1</sup> The Association of Congenial Diaphragmatic Hernia Research and Advocacy and Support, “What is CDH”, <http://www.cherubs-cdh.org/cdh/overview.shtml>, accessed November 21<sup>st</sup>, 2005

In many cases however the medical establishment may discourage fetal-surgery as an option. According to the American Academy of Pediatrics (AAP),

<sup>2</sup>“A pregnant woman should be discouraged from placing herself at undue risk where the potential benefit to the fetus is remote. Under such circumstances, physicians may refuse to offer such an intervention despite a pregnant woman's insistence that something be done.”

Regardless of the position of the medical establishment, the client has to make a decision which will affect the next steps. The client either agrees with the fetal-surgery recommendation or does not. As mentioned earlier, if the client agrees with the recommendation then there is no moral or ethical dilemma to be considered.

On the other hand if the client disagrees with the recommendation, one must consider the right of the mother and the rights of the fetus. Typical arguments a mother may provide to morally justify her right to refuse fetal surgery include situations where her life, or quality-of-life, is at substantial risk. Other scenarios include situations where there is substantial risk to the mother where minimal benefits for the fetus could be achieved<sup>3</sup>.

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<sup>2</sup> Fetal Therapy-Ethical Considerations, <http://pediatrics.aappublications.org/cgi/content/full/103/5/1061> , accessed November 27th, 2005

<sup>3</sup> Fetal Therapy-Ethical Considerations, <http://pediatrics.aappublications.org/cgi/content/full/103/5/1061> , accessed November 27th, 2005

A secondary argument which defends the mother's right to refuse treatment involves questioning the moral status of the fetus. Some argue that the rights of the fetus are not equal to the rights of the mother, that the unborn child does not have the same rights as an evolved human being.

- 1) <sup>4</sup>"The fetus only becomes a human being at birth; before that, it has no rights (this is the traditional Common law definition)"

In opposition to this there are arguments which defend the fetus' rights to life-saving treatment despite the refusal of the recommendation from the mother. These arguments state that...

- 1) The fetus has a right to life from the moment of conception and at least in some cases, where there is minimum risk to the mother, the fetus has the right to life-saving treatment
- 2) At some point in the development of the fetus it evolves into having a right to life even if the mother refuses the treatment.

Whether the moral status of the fetus is in question or not, we can agree that in almost all cases the mother wants to have a healthy child. If this is not the case then the option of abortion could have been explored earlier in the process. Let us also agree that there are risks to any medical intervention and that one of the goals of medical practice is to reduce

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<sup>4</sup> Course Text: Bioethics in Canada, Bernard M Dickens, Prentice Hall Canada Inc, 1997. page 205

the risk to the patient(s) as much as possible. If the aforementioned is true, then it is also true that fetal surgery may be justified regardless of the moral status of the fetus when there is little or no significant risk to the mother. Further more, the mother may be,<sup>5</sup>“legally obligated in some countries to accept fetal therapy” if they had previously refused abortion as an option.

So under what circumstances would there be a moral and ethical reason to override the right of the mother to refuse treatment. According to the A.A.P. there are three conditions which must be met in order for a medical practitioner to pursue fetal-surgery as an option even if the mother refuses the treatment.

- <sup>6</sup>1) there is reasonable certainty that the fetus will suffer irrevocable and substantial harm without the intervention, 2) the intervention has been shown to be effective, and
- 3) the risk to the health and well-being of the pregnant woman is negligible.

The A.A.P. advises that even if the above criteria are met it is important that any attempts to persuade the mother to consent to the treatment be done in a legal and ethical manner. They also provide a process for review of extreme cases where the medical establishment can review the decisions of the mother and bring potential legal action to force the fetal-surgery treatment.

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<sup>5</sup> Course Text: Bioethics in Canada, Bernard M Dickens, Prentice Hall Canada Inc, 1997. page 286, middle

<sup>6</sup> Fetal Therapy-Ethical Considerations, <http://pediatrics.aappublications.org/cgi/content/full/103/5/1061> , accessed November 27th, 2005

<sup>7</sup>“Some courts in the United States have already forced women to undergo cesarean delivery, an act of surgery on the pregnant woman, to permit immediate treatment of an endangered viable fetus life.”

So there is the legal stand on the issue of Fetal Therapy, and clearly in some cases there have been instances of legally enforced fetal-surgery. Ethical considerations do not always agree with the legal framework that society provides, as the above court decisions have come under much criticism from Bioethic committees.

The best practices are believed to include increased awareness and informed consent from the mother in order to proceed with life-saving fetal-surgery. In at least some cases however, where fetal-surgery could be a viable treatment there are morally justifiable reasons for the mother to refuse such treatment. As mentioned earlier when the treatment represents considerable risk to the well-being of the mother, or if there is no apparent benefit to the fetus, or if the decision of abortion was not ruled out, a mother is morally justified to refuse the recommendation of fetal-surgery.

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<sup>7</sup> Course Text: Bioethics in Canada, Bernard M Dickens, Prentice Hall Canada Inc, 1997. page 286, bottom

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