Development of fetal surgery in Ecuador, collaboration between health care and academia, a good practice

Desarrollo de la cirugía fetal en Ecuador, colaboración entre la asistencia y la academia, una buena práctica

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ABSTRACT
In Ecuador, approximately 250,000 children are born every year. In 2022, there were 1,609 deaths of children under one year of age. Of these deaths, 21.5% were due to congenital anomalies, occupying second place among the ten leading causes of mortality. This reality of fetal, neonatal and infant health has been echoed by international organizations that urge countries to strengthen the timely diagnosis of congenital defects, relying on technological advancement, training of human resources and investment in areas of care of the fetus as a patient, taking into account that some of these defects can be treated in prenatal life, reducing sequelae, and improving the quality of life. In response to these needs, in Ecuador agreements were generated between the University-Academy, Ministry of Public Health-Assistance and private groups dedicated to continuing education, to jointly develop a sustainable fetal health program that benefits fetuses that are carriers of pathologies. In this paper we describe one of the arms of this project that is related to the care of fetuses that can benefit from the advancement of fetal surgery in Ecuador.

Key words: Medicine, fetal, Surgery, fetal, Diagnosis, fetal, Fetal research, Congenital anomalies, Ecuador

INTRODUCTION
An average of 250,000 children are born annually in Ecuador. During the year 2022, there were 1,609 deaths of children under one year of age; of these deaths, 21.5% were due to congenital anomalies, occupying second place among the 10 leading causes of mortality[1,2].

This reality is identified in several Latin American countries, which is why in 2020 the Pan American Health Organization urged countries to strengthen adequate and timely prenatal diagnosis[3].

Prenatal diagnosis is currently considered a new form of care for the benefit of the mother-fetus binomial, resizing the supply of services in favor of the fetus, who is considered a patient. As a consequence of
the advances in prenatal health, different intrauterine management and treatments have been developed to improve the possibilities of intrauterine life and postnatal results.

The history of fetal surgery developed by pediatric surgeons began with Michael Harrison at the University of California and has spread worldwide, maintaining the guidelines of the International Society for Fetal Medicine and Surgery for interventions, these being:

• To have an accurate diagnosis with exclusion of associated anomalies.

• To know the natural history of the disease and the established prognosis.

• That there is no effective postnatal therapy.

• Intrauterine surgery proved to be feasible in animal models and reverses the harmful effects of the alteration.

• The procedure will always be performed by a multidisciplinary team with strict protocols, approved by an ethics committee and with parental consent⁴.

The pathologies that have proven to have a benefit with fetal therapy were also established and are shown in Table 1.

**Methodology**

An ecological cross-sectional analytical time series study was carried out, in which data recorded from administrative and legal series of the training process and participation agreements to strengthen interinstitutional fetal medicine in Ecuador was obtained. The article describes in a systematic way the steps taken to generate a sustained advance in fetal surgery in Ecuador, developed by our working group in conjunction with the University, and how continuing education processes have allowed the formation of a Fetal Pathology Management Network.

**Step 1: Implementation of fetal diagnostic units**

The first step was to implement prenatal diagnostic units with a global vision, with a clinical management process mentality that implies knowledge in fetal medicine, information and psychological aspects for parents, multidisciplinary relationship with other specialists, pro-

<table>
<thead>
<tr>
<th>Pathology</th>
<th>Effect on the fetus</th>
<th>Justification of therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monochorial pathology</td>
<td>TTTS or oligohydramnios-polyhydramnios sequence, hemodynamic changes, premature delivery</td>
<td>Stopping transfusion between twins, reversal of HF, prevent neurological damage, delay delivery</td>
</tr>
<tr>
<td>Twin-twin transfusion syndrome (TTTS)</td>
<td>Risk of damage to the healthy fetus</td>
<td>Decrease risk of healthy fetus (feticide)</td>
</tr>
<tr>
<td>Acardiac fetus and discordant malformation</td>
<td>Preterm delivery</td>
<td></td>
</tr>
<tr>
<td>Congenital diaphragmatic hernia (CDH)</td>
<td>Hypoplasia, pulmonary hypertension</td>
<td>Reversing pulmonary hypoplasia and preventing pulmonary hypertension</td>
</tr>
<tr>
<td>Lower urinary tract obstruction (LUTO)</td>
<td>Renal damage, pulmonary hypoplasia due to oligohydramnios</td>
<td>Prevent kidney damage, restore the amount of AF</td>
</tr>
<tr>
<td>Thoracic lesions</td>
<td>Pulmonary hypoplasia (space-occupying mass), hydrops due to venous return disturbance</td>
<td>Preventing pulmonary hypoplasia and heart failure</td>
</tr>
<tr>
<td>Sacrococcygeal teratoma</td>
<td>Cardiac insufficiency, fetal anemia</td>
<td>Prevent anemia, prevent heart failure, prevent polyhydramnios</td>
</tr>
<tr>
<td>Neural tube defect</td>
<td>CSF leakage, causing Chiari malformation and ventriculomegaly</td>
<td>Cover exposed spinal cord, stop CSF leakage, prevent ventriculomegaly and reverse cerebellar herniation</td>
</tr>
<tr>
<td>Cardiac malformations</td>
<td>Critical lesion with hypoplasia and irreversible damage</td>
<td>Prevent hypoplasia</td>
</tr>
<tr>
<td>Chorioangioma</td>
<td>High output heart failure, polyhydramnios</td>
<td>Prevent HF, prevent hydrops</td>
</tr>
<tr>
<td>Amniotic flanges or bands</td>
<td>Progressive constrictions, irreversible neurological lesions, vascular damage</td>
<td>Prevent limb deformities and loss of function</td>
</tr>
</tbody>
</table>

CSF: cerebrospinal fluid, HF: heart failure, AF: amniotic fluid. Modified by author from Deprest et al (5)
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Regionalized management of fetal pathology in the prenatal area, follow-up and postnatal management, seeking consensual and shared obstetric decisions between the health team and the parents. From this level, each specific case has access to subspecialty levels of different complexity, both for making management decisions and for informing parents, but without losing the global concept and the particular character of the fetal patient in its indissoluble binomial with the mother. Thus, it was proposed that fetal pathology cases should be handled from a clinical management process concept.

In this process, the Fetal Diagnosis Unit located in the Isidro Ayora Gynecological and Obstetric Hospital in the city of Quito was established based on an agreement between the Central University of Ecuador and the Ministry of Health to provide care and to train specialists in the field of obstetric ultrasound and fetal medicine.

The process is expanding in the care units of the public and complementary health network in Ecuador, always hand in hand with training by the Faculty of Medicine of the Central University.

**STEP 2: CONTINUING EDUCATION IN FETAL MEDICINE AND THE INITIATION OF SURGICAL FETAL THERAPY**

Once the Fetal Diagnosis Unit was established with the support of the academy, assistance and teaching activities began. Almost immediately, the need to move from diagnosis to fetal management and therapy was observed, and it was considered vital to have personnel trained in fetal therapy. In addition, it was necessary to strengthen the knowledge of the professionals who were part of the unit in fetal health issues, so several members of the team began training processes within and outside the country.

Once the health professionals were trained and maintaining the coordinated work with the academy in response to the co-participation agreement, the first surgery was performed in July 2020 by our group. It was a placental laser for twin-twin transfusion syndrome and so far at least 41 intrauterine procedures have been performed, among which laser surgery in monochorial pathology ranks first (Figure 1), followed by the repair of neural tube defects myelomeningocele, which has been performed with the open technique (Figure 2). Thoracoamniotic shunts have been placed in hydrothorax, endotracheal balloon has been inserted in cases of congenital diaphragmatic hernia to improve the postnatal prognosis of these newborns (Figure 3), diagnostic cystoscopies were performed, one of which was also therapeutic. Although not considered as surgery, but implying previous preparation and experience, we performed intrauterine blood transfusions and thoracentesis.

**STEP 3: CONSTITUTION, FORMATION AND INAUGURATION OF THE NATIONAL CENTER FOR FETAL MEDICINE AND SURGERY**

From the first fetal surgery performed by our group in 2020, work began to create a national Center that could respond to the public health needs of our country.

The justification for the creation of a National Center for Fetal Medicine and Surgery was not only based on the right to health and the vision of the fetus as a patient but also, based on a cost-effectiveness analysis, to provide timely prenatal care to reduce the number of sequelae and preterm deliveries resulting from traditional management. In some pathologies, such as twin-twin transfusion syndrome, it is possible to reduce the number of days of neonatal intensive care and the public health and social costs.

This project had an echo in the health authorities, who gave all their support for the achievement of this project. The investment included:

- Differentiated physical spaces or areas that allow offering rapid quality care with warmth, respecting confidentiality and favoring multi-

**Table 2. Summary of fetal procedures performed between July 2020 and November 2023.**

<table>
<thead>
<tr>
<th>Pathology</th>
<th>Procedures</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monochorial pathology</td>
<td>Placental laser</td>
<td>20</td>
</tr>
<tr>
<td>Neural tube defect (NTD)</td>
<td>NTD repair, open technique</td>
<td>9</td>
</tr>
<tr>
<td>Congenital diaphragmatic hernia</td>
<td>Endotracheal balloon placement</td>
<td>2</td>
</tr>
<tr>
<td>Lower urinary obstruction</td>
<td>Cystoscopy</td>
<td>2</td>
</tr>
<tr>
<td>Hydrothorax</td>
<td>Thoracoamniotic catheter</td>
<td>1</td>
</tr>
<tr>
<td>Hydrothorax</td>
<td>Thoracentesis</td>
<td>3</td>
</tr>
<tr>
<td>Bronchopulmonary sequestration</td>
<td>Laser ablation of nutrient vessel</td>
<td>1</td>
</tr>
<tr>
<td>Fetal anemia</td>
<td>Intrauterine fetal blood transfusion</td>
<td>4</td>
</tr>
</tbody>
</table>

HGONAV: HGONA- MFQ data, reported by the author

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disciplinary care, counseling and support to parents.

- Equipment: fetal health requires the use of the latest technology for both diagnosis and surgery, the use of appropriate devices to reduce the risks of the procedures.

- Human resources with knowledge in fetal health and diagnostic procedures and fetal therapy, as well as the sensitivity to accompany parents during their pregnancy.

The Nueva Aurora Pediatric Obstetric and Gynecological Hospital ‘Luz Elena Arismendi’ was designated as the hospital where this center would be developed. And with an investment of approximately USD 568,329.16, the National Center for Fetal Medicine and Surgery was inaugurated on October 31, 2023.

**Conclusions**

- The implementation of fetal surgery services should be the result of a systematic process that firstly allows the training of human talent from universities and in partnership with hospitals of the health network.

- The sustainability of the process is achieved by the participative association between academia, health care and private areas.

- In Latin American countries, in order to optimize both training and assistance resources, reducing the costs generated by fetal surgery by working jointly with professionals from the public and private areas, in a national center where the necessary infrastructure to carry out these surgeries is implemented, seems to be a cost-effective practice.

**Figure 1. Placental Laser for TTTS (twin-twin transfusion syndrome):** a. recipient fetus with polyhydramnios; b. fetal surgery team; c. identification of interfetal vascular communications; d. post-surgical control with normalization of amniotic fluid in both fetuses. This surgery has shown benefit in the management of monochorionic pathology. The case presented was in Quintero stage II (6).
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**Figure 2.** Myelomeningocele repair with open fetal surgery technique: a. fetal spine with lumbosacral neural tube defect; b. fetal head with bilateral ventriculomegaly; c. visualization of the defect through the hysterotomy; d. end of neurosurgery, defect repaired by planes; e. the scar is observed on the skin of the newborn; f. fetal surgery team. Intrauterine repair was shown to reduce the need for ventriculo-peritoneal shunt valve placement and increase the chances of independent ambulation (7-8). The images correspond to a case referred to our center from eastern Ecuador.

**Figure 3.** Sequence of endotracheal balloon (FETO) placement for congenital diaphragmatic hernia: a. vocal cords; b. trachea; c. insertion of the balloon into the trachea; d. balloon inflated between the carina and the vocal cords; e. balloon prior to removal, laser fiber to deflate; f. balloon removed; g. image of the chest with CDH (h: heart, cl: contralateral lung, s: stomach, sp: spleen, l: liver, b: intestine); h endotracheal balloon control. Studies have shown that FETO is associated with increased survival of fetuses with severe CDH, from 40% to 15% without therapy. This case had severe pulmonary hypoplasia (9-10).
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