

BABIES WITH BRAIN DAMAGE WHO CAN NOT SWALLOW

Surgical management

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Abstract – Background: Neonates with severe neurological impairment are often unable to swallow, necessitating gastrostomy for feeding. Because of the risk of developing severe reflux, this procedure is often associated with fundoplication. **Objective:** To assess the safety and efficacy of gastrostomy and Nissen fundoplication in 22 neonates with swallowing difficulties due to serious neurological impairment. **Method:** All children underwent an initial period of nasogastric feeding and after informed consent underwent gastrostomy and Nissen fundoplication. **Results:** There were no significant intraoperative complications. There were two cases of postoperative peristomy leakage. Of the 22 neonates 16 were alive four months after surgery. Six neonates died of complications due to underlying disease. **Conclusion:** We concluded that gastrostomy and Nissen fundoplication are safe procedures and help parents give a better care to these children.

KEY WORDS: gastrostomy, newborn, brain damage, fundoplication, gastroesophageal reflux.

Recém-nascidos com lesão cerebral que não deglutem: manejo cirúrgico

Resumo – Introdução: Neonatos com dano neurológico são frequentemente incapazes de deglutir necessitando de gastrostomia para alimentação. Devido ao risco de refluxo grave, esse procedimento é associado à fundoplicatura. **Objetivo:** Avaliar a segurança e eficácia da gastrostomia com fundoplicatura Nissen em 22 neonatos com dificuldades de deglutição devido à lesão neurológica grave. **Método:** Todos os neonatos foram submetidos a um período inicial de alimentação por sonda nasogástrica e, após consentimento informado, foram submetidos a gastrostomia com fundoplicatura Nissen. **Resultados:** Não houve complicações intra-operatórias significativas. Houve dois casos de vazamento pós-operatório da ostomia. Dos 22 neonatos, 16 estavam vivos 4 meses após a cirurgia. Seis neonatos morreram por complicações devido à doença de base. **Conclusão:** A gastrostomia com fundoplicatura Nissen é procedimento seguro e ajuda os pais a darem melhor cuidado a crianças com lesão neurológica.

PALAVRAS-CHAVE: gastrostomia, recém-nascido, dano encefálico, fundoplicatura, refluxo gastroesofágico.

Neonates with congenital abnormalities and/or severe neurological impairment frequently cannot swallow after birth¹. In these neonates, oral feeding is associated with hypoxemia and aspiration pneumonia, which is a serious complication reported in up to 20% in this population^{1,2}. Considering this, the establishment of an enteral route for feeding is mandatory, either by inserting a nasogastric tube or by performing a surgical gastrostomy^{3,4}. Besides, 65% of neurologically impaired neonates have gastroesophageal reflux and gastrostomy is frequently compli-

cated by reflux, raising its incidence to more than 70%^{2,5}. This condition is a major factor in the long-term care and quality of life of these infants⁶, so that, some authors, advocate routine anti-reflux procedure associated with gastrostomy, although this is still controversial⁷.

Surgical management of gastroesophageal reflux is reported to result in significant clinical improvement of 84.6% of neurologically impaired infants, decreasing the respiratory complications and improving quality of life^{6,7}. On the other hand, while medical therapy with proton

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pump inhibitors have a positive impact on symptoms, the recurrence rate within the first year reaches up to 80%⁸. Furthermore, not only reducing acid secretion has failed to reduce pulmonary aspiration and provide adequate nutrition, but also, these medications are expensive and have side effects in long term therapy^{9,10}.

The objective of this study is to evaluate the safety and efficacy of performing gastrostomy and Nissen fundoplication in neonates with swallowing difficulties due to serious neurological impairment.

METHOD

The charts of 22 neurologically impaired neonates operated at the Center for Integral Attention to the Health of Women at the State University of Campinas (CAISM-UNICAMP), from January 2002 to July 2007 were retrospectively reviewed. This study was approved by the Committee for Medical Ethics of UNICAMP.

Data collected from the charts included: maternal age, gestational background, prenatal consultations, prenatal diagnosis and delivery, birth weight, sex, APGAR score (1st and 5th minute), CAPURRO, presence of previous operations, age and weight at the time of operation, ASA score, duration of anesthesia and operation, intraoperative complications and postoperative outcome, presence of associated chromosomal abnormalities and final diagnosis, time between surgery and hospital discharge and total length of hospitalization.

The option of gastrostomy with Nissen fundoplication was offered to the parents of 28 severe neurologically impaired neonates after a thorough evaluation confirmed that they would not be able to develop a normal feeding pattern. Initially, the mother was invited to participate in the care of his/her child at the Neonatal Intensive Care Unit (NICU). After a period of maternal orientation and training, during which the neonate was fed through a nasogastric feeding tube, the option of surgery was offered to the mothers. Six mothers chose to continue with nasogastric tube feeding and so their neonates were excluded from the study.

No pre-operative evaluation of gastroesophageal reflux was done. All the babies included had severe neurological impairment and, thus, were at high risk for reflux, which would be increased both in frequency and severity after gastrostomy. Considering this, we decided to perform routinely an antireflux procedure together with gastrostomy as advocated by other authors⁷.

After obtaining the parent's informed consent, a Stamm gastrostomy associated with a short and floppy Nissen fundoplication was performed in the remaining 22 newborns. Folley catheter size varied between 10 and 14 and feeding was initiated between 24 and 48 hours after surgery with milk appropriate for the child's age.

RESULTS

Average birth weight was 2807g (905g to 4180g). There were thirteen females (59%) and 9 males (41%). Prenatal ultrasound was performed in 20 of these children and the results are shown in Table 1.

Delivery was by vaginal route in 9 (41%) and by cesarean section in the remaining 13 (59%). The indications for C-section were prenatal diagnosis showing fetal malformation in 7 (54%), cephalo-pelvic disproportion in 3 (23%) and acute fetal distress in 3 (23%).

First and fifth minute APGAR scores were lower than 8 in 12 neonates. Nine children were preterm (59%) and thirteen were considered term (41%). The average CAPURRO gestational age was 36 weeks (from 31 to 41 weeks). Sixteen were adequate for gestational age (73%), 5 were big for gestational age (22.5%) and 1 was small for gestational age (4.5%).

Besides their background condition, further neurological damage was caused by intraventricular bleeding in four of the severely anoxic children (18%): grade I in one, grade II in another and grade IV in the remaining two.

Ten neonates (45%) needed surgery prior to the gastrostomy and Nissen fundoplication: four encephalocele corrections, three myelomeningocele corrections, five had

Table 1. Pre and post-natal diagnoses in 22 newborns undergoing gastrostomy with Nissen fundoplication.

Diagnosis	Prenatal n (%)	Neonatal n (%)	No prenatal n (%)
Severe neonatal hypoxia	6 (30%)*	7 (32%)	1 (50%)
Hydrocephalus	5 (25%)	5 (23%)**	
Encephalocele	4 (20%)	4 (18%)	
Chromosomopathy	4 (20%)	4 (18%***)	
Fetal hydrops	1 (5%)	1 (4.5%)	
Metabolic encephalopathy	0	1 (4.5%)	1 (50%)
Total	20 (100%)	22 (100%)	2 (100%)

*Normal prenatal ultrasound; **Three were associated with myelomeningocele; ***Two 18-trisomy, one 13-trisomy and one 21-tetrasomy.

Table 2. Surgical results observed in 22 newborns undergoing gastrostomy placing and Nissen fundoplication.

Mean weight at operation	3690 g (1550–4630 g)
Mean age at operation	37 days (8–90 days)
Length of operation	80 min (55–135 min)
ASA score	2 ASA II, 14 ASA III e 6 ASA IV
Length of anesthetic time	121 min (70–180 min)
Surgical complications	2 periostomy leaks

a VP shunt placed to correct isolated or associated hydrocephalus, one underwent a right pyelostomy and correction of anal imperforation. Two neonates (9%) also had a tracheostomy performed with the gastrostomy and Nissen fundoplication.

Average age at the surgical procedure was 37 days (8 to 90 days) and average weight was 3690g at procedure (1550g to 4630g). Two neonates were classified as ASA II (9%), 14 as ASA III (64%) and 6 as ASA IV (27%).

Mean duration of anesthesia and of surgical procedure were, respectively, 121 minutes (from 70 to 180 min) and 80 minutes (55 to 135 minutes) (Table 2). Blood loss was described as minimal in all cases and there were no significant intraoperative complications.

There were two postoperative complications (9%), both due to leakage at the gastrostomy site and periostomy infection. The mean time between surgery and hospital discharge was 12 days (from 2 to 30 days). Total hospitalization time averaged 49 days (from 20 to 105 days).

Long term follow-up of these patients is difficult because most of them come from other cities and the families find it very hard to come for frequent outpatient visits. As a result, follow-up was available for only four months in the majority of the patients, corresponding to the first outpatient visit after discharge. In this short-term postoperative follow-up, 16 neonates (73%) were alive after four months and there were no complications related to gastroesophageal reflux, such as recurrent respiratory infection or hypoxemia, during this period.

Three neonates (13.5%) died while still at the hospital due to the underlying disease, an average of 14 days after the surgery. Three additional patients died at home 2 months after discharge. No deaths could be attributed to the operation itself.

DISCUSSION

Ultrasound is a routine prenatal exam that allows early diagnosis of several fetal abnormalities. The diagnosis of fetal anomalies provides a better evaluation of the gestation and a better preparation in the approach of the neonate by the pediatric surgeon and his team. This prenatal preparation goes through genetic investigation, maternal

and relatives' psychological support providing reduction of the parents' anxiety levels, besides orientation about the diagnosis, evolution and fetal prognosis^{11,12}.

Among the congenital abnormalities identified by prenatal ultrasound, central nervous system and neural tube closing defects are the most frequent. The presence of these fetal abnormalities is usually associated with a poor postnatal prognosis and severe feeding problems¹³. Often, respiratory disabilities and intractable gastroesophageal reflux complicate those sucking and swallowing impairments¹⁴.

Severe neonatal anoxia associated or not with prematurity, may lead to intraventricular hemorrhage which is another frequent cause of neurological damage and secondary feeding problems^{12,15}. Severe malnutrition and chronic aspiration are common consequences of these problems, making home care of these very sick infants very troublesome.

Due to these problems, most of these children are better fed through an enteral route. This can be accomplished either through a nasogastric tube or by surgically placing a gastrostomy.

In our NICU, the choice of the best procedure is a shared responsibility between the doctor and the family. Initially, after confirmation that the neonate will not develop normal feeding ability, a nasogastric tube is inserted and the mother (or another close relative) is invited to participate in the care of the child. During this period she is instructed on the details of enteric feeding. After a variable adaptation time, the parents are informed of the possibilities, advantages and risks of placing a gastrostomy. Together with the NICU team they make a decision on whether to operate or not.

From the medical point of view, the most appropriate procedure in neonates that cannot swallow is gastrostomy placing. It is associated with a lower incidence of respiratory problems and, because of its larger diameter, the probe is less prone to clogging⁴. The procedure can be accomplished endoscopically, by percutaneous puncture^{16,17} or surgically by either laparoscopic or open surgery¹⁸.

Presently, the laparoscopic route is most appropriate for the surgical treatment of various abdominal problems in children^{19,20}. However, the small size of the equipment needed is not available in every institution. Due to these drawbacks we normally use open surgery for performing gastrostomy with Nissen fundoplication in small babies.

It is well known that neurological impaired children have a high incidence of gastroesophageal reflux. Although the initial treatment for GER, especially in newborns is clinical²¹, surgical treatment may be indicated in cases where anatomical disorders are present or when

clinical treatment is ineffective and associated with life-threatening conditions^{22,23}. In these instances, it has been demonstrated that the Nissen fundoplication can be accomplished safely with a low incidence of complications²⁴. Besides, antireflux procedure has been shown to significantly improve the life quality of these babies from the care-giver's point of view with a high index of satisfaction⁶.

Gastrostomy can cause anatomical alterations of the stomach, which favor the development of gastroesophageal reflux¹⁵. It is a matter of dispute whether a Nissen fundoplication should or should not be associated when performing a Stamm gastrostomy²⁵⁻²⁷. We believe that newborns having this particular problem have a high probability of massive reflux, performing a gastrostomy is a potential life-threatening situation, therefore, whenever the clinical status of the babies permit, prophylactic Nissen fundoplication should be associated.

In our institution, prenatal diagnosis was accomplished in 90% of the pregnant women^{17,23}, identifying, in 70%, serious malformations: five severe hydrocephalus, of which three were associated with myelomeningocele; four encephalocele; four chromosomopathies, one trisomy of the 13 (Patau), two trisomies of the 18 (Edwards), one tetrasomy of the 21 and a fetus with hydrops. All these diagnoses were confirmed in the neonatal period and most of these neonates were AIG and born to term, without difference in sex distribution. Of the normal neonates, seven suffered anoxia. Of these, one had not gone through the prenatal program and four had hemorrhage, three of these being serious. These results reinforced the importance of the pre-natal diagnosis and of the attendance of the gestations of fetuses with congenital defects by the pediatric surgeon¹¹.

Although the neonates included in this study were considered of major anesthetic risk (91% were graded ASA III and IV), gastrostomy with Nissen fundoplication was performed safely with no major complications or deaths attributable to the operation. The length of operation was acceptable (average 80 minutes) even though they were performed mostly as teaching cases by the senior resident. Also, the incidence of postoperative complications was low, consisting of only two periostomy leaks. Similar results were reported by Schatzlein et al.²⁶ and Bordewick et al.²² who noted that gastrostomy leak and periostomy infection are the most frequent complications in this type of surgical procedure.

The prolonged total time of hospitalization (49 days) was due mostly to problems associated with the underlying conditions. However, postoperative in-hospital stay was short (average 12 days) including the time spent in training the relatives on how to deal with the gastrostomy tube.

Short time on follow-up is always a problem when evaluating the outcome of a surgical procedure. In this report, however, it should be noted that the objective of the operation was not long time control of symptoms. Instead, it was performed in order to offer the families an easier way to care for these babies at home, during the often-limited life span they are expected to have. In our opinion, this objective was accomplished in every case.

Many ethical considerations are involved in the indication of surgical procedures in neonates with serious congenital defects such as thoracic myelomeningocele associated with severe hydrocephalus, gastrointestinal abnormalities associated with 13 or 18-trisomy and very low birth weight newborns with grade III or IV intraventricular hemorrhage²⁸. In some European countries, because of a very dismal prognosis, these neonates are offered only minimal care, excluding them from any major surgical procedures^{29,30}. We believe, with others, that no heroic measures are to be taken with these newborns. However, once these babies are born, creating an easier way to feed them should be included in the "minimal care" criteria, with the aim to improve the quality of life for both the children and their caregivers. Because of the fact that in many countries no major procedure is performed in these babies there are very few studies on the surgical management of their swallowing and gastroesophageal reflux. The decision to operate on these children can vary greatly from country to country, raising intense ethical and legal issues. These should be faced by the whole health team with a great dose of thoughtfulness, respecting the family wishes and beliefs, with the clear intention of helping them to make a fully informed and conscious decision regarding their child's limited future¹³.

The prenatal diagnosis of congenital abnormalities has strongly influenced the decision-making process regarding the management of fetuses and neonates with severe congenital problems¹⁸. The flow of information should be uniform and the management plan should always be discussed and agreed upon by all members of the health care team and the family.

In countries where abortion is legal, fetuses with serious abnormalities diagnosed *in-utero* are not allowed to develop. In Brazil, where abortion is an illegal practice, many neonates are born with serious limiting disabilities. These children will often need special care facilities and countless hospitalizations and operations throughout their entire lives.

In conclusion, the data presented here indicates that gastrostomy with Nissen fundoplication represents a safe surgical option for neonates who can not swallow when performed in common agreement with the health care team and the parents.

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