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Short-term and family-reported long-term outcomes of simple *versus* complicated gastroschisis

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ABSTRACT

Background: Our goal is to determine short- and long-term outcomes of simple gastroschisis (SG) and complicated gastroschisis (CG) patients including quality of life (QoL) measures, surgical reoperation rates, and residual gastrointestinal symptom burden.

Materials and methods: Retrospective chart review of patients who underwent surgical repair of gastroschisis between January 1, 2009, and December 31, 2012, was performed at a quaternary children's hospital. Parent telephone surveys were conducted to collect information on subsequent operations and current health status as well as to assess QoL using two validated tools.

Results: Of 143 patients identified, 45 (31.5%) were reached and agreed to participate with a median follow-up age of 4.7 y. Although CG was associated with short-term outcomes such as longer length of stay, longer days to feeds, and higher complication rates, there were no major differences in long-term QoL outcomes when comparing SG and CG. Children with CG experienced abdominal pain/gas/diarrhea more often than those with SG and required more major abdominal procedures than those with SG (15% *versus* 0%, $P = 0.009$).

Conclusions: Despite worse short-term outcomes, presence of certain gastrointestinal symptoms, and need for more surgical interventions for patients with CG, and overall QoL scores were reassuringly similar to those with SG.

Introduction

Gastroschisis, the most common congenital abdominal wall defect, results in the herniation of uncovered abdominal viscera through a defect usually to the right of the umbilicus.[1] The condition affects approximately 3.1/10,000 live births in the United States, and the prevalence has been increasing over the last half century.[2,3] Before the 1970s, gastroschisis survival was poor with very few children surviving the neonatal period.[4] Contemporary survival rates are well over 90% because of advances in neonatal intensive care, surgical care, and the introduction of parenteral nutrition (PN).[1]

Because of the improving survival rates and the ability to diagnose gastroschisis prenatally as early as 12 wk, focus has

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shifted from survival to clinical outcomes such as total length of hospital stay, superior type of surgical closure, and preventing PN dependence.[5] Short-term physical and neurodevelopmental outcomes up to 2 y have been extensively studied, and research suggests that although children may experience an early growth delay, early neurodevelopmental outcomes are similar when compared to children without gastroschisis of the same gestational age.[6-8]

There is limited information available on long-term outcomes of gastroschisis patients, especially quality of life (QoL) outcomes. Most published studies have relatively small sample sizes, contain older data, and include patients with other abdominal wall defects such as omphalocele.[9,10] Carpenter *et al.* recently studied outcomes using a validated survey, the Pediatric Quality of Life Inventory (PedsQL), to assess QoL over a 3-7 y follow-up period. Their research suggests that simple gastroschisis (SG) and complicated gastroschisis (CG) patients have similar QoL.[11] However, residual gastrointestinal (GI) symptom burden has not been assessed in a standardized manner using a validated assessment tool.

The purpose of this study is to determine long-term outcomes for patients with gastroschisis, including QoL measures, surgical reoperation rates, and residual GI symptom burden, and to compare outcomes between SG and CG patients. We hypothesized that patients with CG would have worse long-term outcomes compared to those with SG. We designed a combined chart review and parent telephone survey to assess the aforementioned outcomes.

Methods

Patient selection

Institutional review board approval was obtained for the chart review and phone survey protocol. Patients who underwent surgical repair of gastroschisis at a quaternary children's hospital between January 1, 2009, and December 21, 2012, were identified using the International Statistical Classification of Disease codes, ninth revision, (diagnosis code 756.73 and procedure code 54.71). The time frame was chosen so that at least 3 y of follow-up data would be available. The study encompassed a 4-y time frame and represented patients cared for in our two-hospital system by 15 surgeons. There was no standardized approach in place for the management of gastroschisis, but most primary closures were performed under general anesthesia and predominantly in the operating room. Silo placements were typically performed at the neonatal intensive care unit under sedation with or without intubation. Silo reductions were performed daily until the bowel was reduced, and then, patients were typically taken to the operating room for closure. To capture at least 3 y of follow-up, more contemporary strategies such as sutureless closures are not reflected in this study. We excluded patients who were diagnosed with other abdominal wall defects such as omphalocele, patients who underwent surgical repair at outside hospitals, and patients who were deceased.

Study design and data collection

Preliminary chart review for short-term outcomes

Retrospective chart review was performed, and data from the neonatology and surgery records were collected. Birth history, surgical details, outcomes, and complications were collected. Patients were classified as either SG or CG. As originally described by Molik *et al.*,[4] gastroschisis was considered complicated if at least one of the following abnormalities was present: intestinal atresia, necrosis, volvulus, or perforation.

Phone survey for long-term outcomes

Using telephone contact information from the chart review, parents/guardians were called three times on three separate occasions at least a week apart. Voicemails were left with a contact number when available, and no personal health information was shared on the voicemail messages.

Once a patient's family was reached and the parent's identity was confirmed, oral consent was obtained. Parents were informed that their participation was voluntary, they could stop the survey at any time, and the interview would take approximately 30 min to complete. They were given the option of scheduling a later date and time if preferred. At the end of the interview, parents were given the option of receiving a phone call from a surgeon if they had any additional clinical questions. Interpreters were available by phone for multiple languages as needed.

The interview assessed the child's current health status including: weight, height, medical conditions, medications, and surgical history. Other variables included age of toilet training completion, residual hernia symptoms, and concern about cosmetic appearance (see Appendix A).

Two validated surveys were administered. The PedsQL (version 4.0; Mapi Research Trust, Texas A&M University, College Station, TX) was administered to assess QoL, and the PedsQL Gastrointestinal Symptoms Module (GSM; version 3.0; Mapi Research Trust, Texas A&M University, College Station, TX) was used to assess current symptom burden.[12,13] The Parent Report for Toddlers (2-4 y old) and the Parent Report for Young Children (5-7 y old) were used in this study, and both the versions have the same dimensions. The QoL Inventory has four dimensions: physical, emotional, social, and school functioning. The GSM has 14 symptom categories including abdominal pain, gas and bloating, diarrhea, and constipation. A Likert scale was used to describe frequency of problems/symptoms in the past month.

Scores for both the surveys were calculated using the scoring manual provided, which converts parent responses into a number from 1 to 100, with higher scores indicating better QoL and less GI symptom burden.[12]

Secondary chart review for long-term outcomes

After phone call follow-up was completed, the charts of patients who could not be reached were reviewed to determine if the patients had any follow-up with the institution, such as emergency room visits, hospitalizations, or clinic appointments. Variables collected included date of last follow-up, age at follow-up, subsequent surgeries, residual hernia, and small-bowel obstruction (SBO) hospitalizations. Those