

# Ascertainment of Gastroschisis Using the ICD-9-CM Surgical Procedure Code

Charles A. Williams,<sup>1\*</sup> Kimberlea W. Hauser,<sup>2</sup> Jane A Correia,<sup>3</sup> and Jaime L. Frías<sup>2</sup>

<sup>1</sup>Division of Genetics, Department of Pediatrics, University of Florida College of Medicine, Gainesville, FL

<sup>2</sup>Birth Defects Center, Department of Pediatrics, University of South Florida, Tampa, FL

<sup>3</sup>Florida Birth Defects Registry, Bureau of Community Environmental Health, Florida Department of Health, Tallahassee, FL

**OBJECTIVE:** To determine the effectiveness of using the ICD-9-CM procedure code 54.71 for case ascertainment of gastroschisis. **METHODS:** Using procedure code 54.71, we queried a statewide hospital discharge database to identify all cases coded as undergoing surgical repair of gastroschisis. Each retrieved case was verified as having gastroschisis by review of the hospital record. All gastroschisis cases were then matched to the Florida Birth Defect Registry (FBDR) dataset. This registry uses a passive system of multiple data sources and employs the ICD-9-CM diagnostic code 756.79 to identify gastroschisis and other abdominal wall defects. **RESULTS:** Of 93 cases identified by using code 54.71, 92 were confirmed by record review to have gastroschisis. The FBDR identified 87 of the 92 cases (95%). The FBDR missed three of the remaining five cases because of linkage difficulties between inconsistent data elements in the respective data files. The other two cases were not identified by the FBDR because the source database (AHCA discharge) truncates the entry of ICD-9-CM diagnostic codes when more than 10 of them are listed in the medical record. **CONCLUSIONS:** Use of the surgical procedure code was demonstrated to be superior to the diagnostic code as a method for identification of gastroschisis cases. The same approach may be useful in the detection of malformations other than gastroschisis.

## INTRODUCTION

Gastroschisis is usually identified by prenatal ultrasound and typically occurs as an apparently isolated defect, usually involving an area of the abdominal wall just rightward of the umbilical cord. At the time of birth, protrusion of a portion of the intestines and other abdominal organs is amenable to surgical correction that typically has a good clinical outcome (Fisher et al., 1996; Boyd et al., 1998; Singh et al., 2003). Associated anomalies are present in 5–30%; the most common being small bowel atresias (Hoyme et al., 1981; Fisher et al., 1996; Barisic et al., 2001; Sipek et al., 2002).

In the ICD-9-CM diagnostic code system, gastroschisis must be coded as 756.79, indicating that it is a malformation involving “other congenital anomalies of the abdominal wall.” This code does not distinguish between gastroschisis, omphalocele or exomphalos. However, the ICD-9-CM coding system also includes a system for procedures (usually surgical), and this system specifies a numeric code, 54.71, that is specific for surgical repair of gastroschisis. In this study, we determined the accuracy of code 54.71 for identifying cases of gastroschisis and compared it with the ability of ICD-9-CM code 756.79 to identify the same cases in our passive birth defects registry.

## METHODS

This study was based on the surveillance, from birth to one year of age, of all infants born in Florida from January 1, 2000 to December 31, 2000. Cases of gastroschisis were first identified by using ICD-9-CM procedure code 54.71 retrieved from the hospital

discharge database of the Agency for Health Care Administration (AHCA). This database records the first 10 ICD-9-CM diagnostic and procedure codes for every child discharged from Florida hospitals. All hospital discharges for infants less than 12 months of age were reviewed. In order to identify all cases in which procedure code 54.71 was recorded for infants born in 2000, it was necessary to review the 2000 and 2001 AHCA datasets, as infants discharged and/or operated upon in 2001 may have been born in 2000.

For each case so identified, copies of selected portions of the hospital record were requested from the hospital's medical records department. Generally, the records reviewed included the discharge face sheet (that listed all ICD-9-CM diagnostic and procedure codes), admission and discharge dictations, physician progress notes, consultant reports, and all written and dictated operative notes. In some cases, the maternal prenatal, obstetrical, and birth records were obtained. This study was approved by the Institutional Review Boards of the University of Florida and the Florida Department of Health. The study was granted a HIPAA waiver for informed consent.

The hospital record for each case was then abstracted by a pediatric clinical geneticist (CAW) in order to validate that gastroschisis was the correct diagnosis. The extent of the gastroschisis defect and degree of intra-abdominal anomalies were determined, usually from information recorded in the

\*Correspondence to: Charles A. Williams, MD, Division of Genetics, Department of Pediatrics, University of Florida, P.O. Box 100296, Gainesville, FL 32610. E-mail: willicx@peds.ufl.edu  
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newborn physical examination and the first surgical operative notes.

All confirmed cases were then matched to the case number identified by the Florida Birth Defects Registry (FBDR) using the AHCA hospital discharge account number, the maternal social security number, or the infant's date of birth. The FBDR uses a passive system based on multiple data sources to identify cases having birth defects, from birth to age one year, for all infants born in Florida. The primary data sources are the Florida Department of Health Office of Vital Statistics, Children's Medical Services program, and the AHCA hospital discharge database. The FBDR identified gastroschisis cases in the above data sources by using ICD-9-CM diagnostic code 756.79. Prevalence rates for gastroschisis were calculated for the years 1997 to 2001 using both FBDR and surgical procedure code ascertainment methods.

## RESULTS

Ninety-three cases were initially ascertained, but one case had abdominal wall complex (the baby had a large abdominal wall and craniofacial disruption), and was therefore excluded. The remaining 92 cases were all confirmed by record review to have gastroschisis. The FBDR identified 142 cases having the 756.79 code (e.g., cases with at least one of the following: gastroschisis, omphalocele, or exomphalos). Within this cohort of 142 cases we were able to match 87 of the 92 cases (95%). Three of the remaining five cases were unmatched because of inconsistent maternal information (e.g., different maternal social security numbers between the birth Vital Statistics and the AHCA hospital discharge records), and this led to a linking problem causing deletion of those records from the FBDR dataset. The other two cases had 10 ICD-9-CM discharge diagnoses, the maximum allowed in the AHCA database, which did not include ICD-9-CM diagnostic code 756.79.

The prevalence rate for gastroschisis in our study population was 4.5 per 10,000 live births. Using a similar methodology involving retrieval of the surgical code, but without case review, gastroschisis prevalence rates for 1997, 1998, 1999 and 2001 were estimated at 3.8, 3.5, 3.4 and 2.9 per 10,000 live births, respectively. The median maternal age was 20.4 years, with 57% of the mothers being under 20 years of age. The diagnosis of gastroschisis was known via prenatal ultrasound study in 94% of 85 informative cases. Thirteen of the 92 cases (14%) had associated major malformations. The male to female ratio was 1.3 to 1.0. Table 1 lists various demographic aspects of the cases.

**Table 1**  
**Summary of selected demographic and obstetrical factors for mothers of infants with gastroschisis, compared to all births in Florida**

	Gastroschisis Cases 2000 N=92 (%)	Florida 2000 Live Births (no birth defects) N=187,067 (%)
Maternal age, yrs (mean)	20.41	27.12
Race and ethnicity		
White, non-Hispanic	62 (68.9)	98,085 (52.5)
Black, non-Hispanic	7 (7.8)	40,996 (22.0)
Hispanic	21 (23.3)	42,401 (22.7)
Other		5,232 (2.8)
Gravida 1	54 (58.7)	62,656 (33.5)
> Gravida 1	38 (41.3)	124,314 (66.5)
Vaginal delivery	33 (35.9)	140,612 (75.2)
C-section delivery	59 (64.1)	46,296 (24.8)

## DISCUSSION

We found that use of the surgical procedure code was an accurate way to ascertain cases of gastroschisis. Abstraction of a total of 93 records, initially identified by this procedure code, confirmed that 92 cases had gastroschisis. Use of this procedure code alone identified more cases than the FBDR, which uses multiple data sources to identify cases based on the ICD-9-CM diagnostic code. Unfortunately, this approach to case ascertainment cannot be applied to birth defects that are not amenable to surgery. For those defects amenable to surgical repair, the approach would also not apply if the surgical procedure code is not very specific or inclusive. For example, repair of atresia of the small intestine can have different procedure codes depending on what type of intestinal resections, anastomoses or ostomy procedures are performed.

The use of the procedure code was helpful in further evaluating the gastroschisis prevalence data obtained from this study. The detection of 92 cases of true gastroschisis gave a prevalence rate of 4.5 per 10,000 live births, during the year 2000. This rate is relatively high, even considering the findings of many recent studies that indicate an increasing prevalence of gastroschisis (Di Tanna et al., 2002; Laughon et al., 2003; Salihu et al., 2003; Goldkrand et al., 2004; Kazaura et al., 2004). Since our study demonstrated that the gastroschisis procedure code was quite specific, and also showed that query of the AHCA hospital discharge data set could identify more cases than our registry's multiple data source system, we were able to use the gastroschisis proce-

procedure code approach to calculate estimated prevalence rates for the 3 years prior to, and the year following, our study. These rates ranged from 2.9 to 3.8/10,000, with the lowest rate observed in the year following our study.

For passive registries, use of the gastroschisis procedure code could be an effective way to revisit past datasets in order to separate cases of gastroschisis from omphalocele. This could be important in evaluating trends in gastroschisis prevalence, and this separation could be done without requiring a labor intensive chart review. Passive registries may also want to consider if use of this procedure code might be added to their future surveillance process since ICD-9-CM code 756.79 continues in use and will not distinguish between cases of gastroschisis and omphalocele.

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