Long Term Follow-up of Morbidity and Quality of Life Associated with Isolated Gastroschisis

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Gastroschisis is a birth defect in which an opening in the abdominal wall allows herniation of the viscera. Prenatal counseling regarding gastroschisis typically discusses that, although these infants often endure a difficult neonatal course, they experience few long-term complications. However, information regarding long-term outcomes is based on limited studies that lack specificity. Therefore, we aimed to study the long-term morbidity and quality of life in children born with gastroschisis in a large and diverse population drawn from the Texas Birth Defects Registry (TBDR). Study packets with informed consent, a questionnaire, and the Pediatric Quality of Life Inventory Generic Core Scale 4.0 (PedsQL 4.0) in English and Spanish were mailed to 1,112 parents of children born with isolated gastroschisis in Texas between 1999 and 2008 via the TBDR. Information was abstracted from the TBDR for 58 mothers of children with gastroschisis who returned study materials. Three hundred fifty five packets were returned to sender, giving a response rate of 7.7%. Children born with gastroschisis had quality of life scores that were not significantly different than expected (p = 0.981). However, factors such as having a learning disability (p = 0.001) and missing school due to gastrointestinal issues (p = 0.020) were found to significantly decrease quality of life. Overall, children with gastroschisis had a significantly increased risk for learning disabilities regardless of whether they were preterm (p = 0.021) or full term (p = 0.021). Additionally, there appeared to be an increased risk for auditory impairment in Caucasian children (p < 0.0001). Therefore, while overall long-term quality of life is not significantly altered for children born with gastroschisis, the previously unreported increased risk for learning disabilities and possible association with hearing impairment are important findings that should be conveyed to prospective parents.

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