Case Report

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Challenges and lessons learnt in the management of an HIV-exposed neonate with gastroschisis in a resource-limited setting: case report

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Introduction and importance: The incidence of congenital abdominal wall defects is increasing, but few cases have been reported in the African population.

Case presentation: The authors report a case of gastroschisis in a term neonate who was delivered through spontaneous vaginal delivery (SVD) in a remote health facility before transfer to a tertiary hospital in Uganda. Although there was no environmental exposure to teratogens, the major risk factor of Gastroschisis, the neonate was low birth weight, HIV-exposed, and the mother had not received folic acid supplementation during the first trimester, known risk factors of gastroschisis. Physical examination revealed intrauterine growth restriction in addition to the findings of the abdominal wall defect.

Clinical discussion: There were many missed opportunities in the management of this case which was marred by delayed essential care of the newborn, delayed surgical repair, and transfer to the tertiary surgical centre. At the tertiary surgical centre, a modified silo technique with delayed secondary closure was used to repair the defect, but the neonate still met its death before completing day 7 of life.

Conclusion: This case of gastroschisis shows how the diagnosis and management of neonates born with major congenital structural abnormalities in resource-limited settings is still desirable due to lack of sophisticated medical care services to assist in early detection during pregnancy and early surgical intervention at birth to prevent associated mortality. The authors discuss the lessons learnt and provide recommendations for improvement in the care of neonates born with abdominal wall defects and other congenital birth defects.

Keywords: abdominal wall defects, case report, gastroschisis, HIV-exposed neonate, intrauterine growth restriction

Introduction

The incidence of gastroschisis and omphalocele, common congenital abdominal wall defects[1–5], is increasing, but few cases have been reported in the African population. Gastroschisis involves herniation of the gut, and possibly the liver and other intra-abdominal organs, through a defect that results from the failure of the formation and development of the ventral body wall during embryogenesis[6,7]. The aetiology of gastroschisis is not well understood; however, it is associated with genetic chromosomal abnormalities due to familial and teratogenic exposure, extreme maternal age, and social demographic factors such as rural residence[1,3,7,8]. Common environmental exposures associated with gastroschisis include alcohol and tobacco use

HIGHLIGHTS

- The incidence of congenital abdominal wall defects is increasing, but few cases have been reported in Africa.
- The aetiology of gastroschisis is not well understood; however, it is associated with genetic chromosomal abnormalities due to familial and teratogenic exposure, HIV exposure, folic acid deficiency, and extreme maternal age.
- Gastroschisis diagnosis and management require sophisticated surgical interventions that are scarce in low-resource settings.
- Detailed antenatal history is needed to identify risk factors for congenital abdominal wall defects, and utilization of cheap and affordable preventive measures like pre-conceptional use of folic acid can prevent abdominal wall defects while second-trimester ultrasound scans can promote early detection before birth.

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during pregnancy and exposure to nitrosamines and cyclooxygenase inhibitors[6,7].

Gastroschisis diagnosis and management require sophisticated surgical interventions[6,9,10] that are scarce in low-resource settings; for example, antenatal prediction through the measurement of maternal serum alpha-fetoprotein and diagnosis by obstetric ultrasonography[3,6,7] is still not feasible for every pregnant woman living in developing countries. This continues to negatively affect birth preparedness and emergency intervention efforts that have otherwise proven successful, with good outcomes among neonates born with gastroschisis[6,9].

We report a case of neonatal gastroschisis presenting with bowel and stomach herniation and describe the challenges and lessons learned in the management of a neonate with an abdominal wall defect in a remote resource-limited setting.

Case presentation

The patient was a four-hour-old male HIV-exposed neonate delivered through spontaneous vaginal delivery. It cried immediately at birth, was pink in colour, active with a recorded APGAR score of 9/10, and had a birth weight of 2.3 kg. The neonate was delivered at a peripheral health facility and referred to the nearest regional hospital for further management of the abdominal wall defect (gastroschisis).

The mother of the baby was aged 19 years, HIV-positive, not on anti-retroviral therapy (ART) during pregnancy (neonates at high risk for HIV infection), a peasant farmer in a rural village in Uganda, para 1 + 0, attended antenatal care and started folic acid in the second trimester (around 16 weeks of gestation) but never underwent obstetric ultrasonography during the entire pregnancy.

On general examination, a term newborn was sick-looking, making normal cry and normal body movements, tachypneic (respiratory rate of 70 breaths per minute), hypothermic (axillary temperature of 32.8°C, was placed near an electric warmer and temperature raised to 36.4°C), had warm extremities with no cyanosis, jaundice, nor dysmorphic features except on the abdomen. Anthropometric measurements: Weight 2.3 kg, length (50.0 cm), weight for height Z-score below negative 3SD. This suggests possible intrauterine growth restriction.

Systemic examinations were not significant, except for the abdomen. Abdominal examination revealed, an obvious abdominal wall defect to the right of the umbilicus measuring ~4.0–4.5 cm in diameter, as shown in Fig. 1. The defect had a protruding intestinal bowel and stomach, which were not covered by any membrane. The intestines were swollen and covered with a thick fibrous peel. These clinical features helped to distinguish gastroschisis from omphalocele, in which the defect in which the defect has no sac covering the intestines[7,8].

The chest was symmetric, tachypneic (respiratory rate, 70 breaths per min), normal in shape, with no lower chest indrawing, and equal air entry bilaterally with no added breath sounds.

Cardiovascular examination was normal with a heart rate of 115 beats per min, normal pulses with normal blood volume, oxygen saturation measured by the pulse oximeter was 93%, heart sounds 1 and 2 were heard, and no added sound was heard.

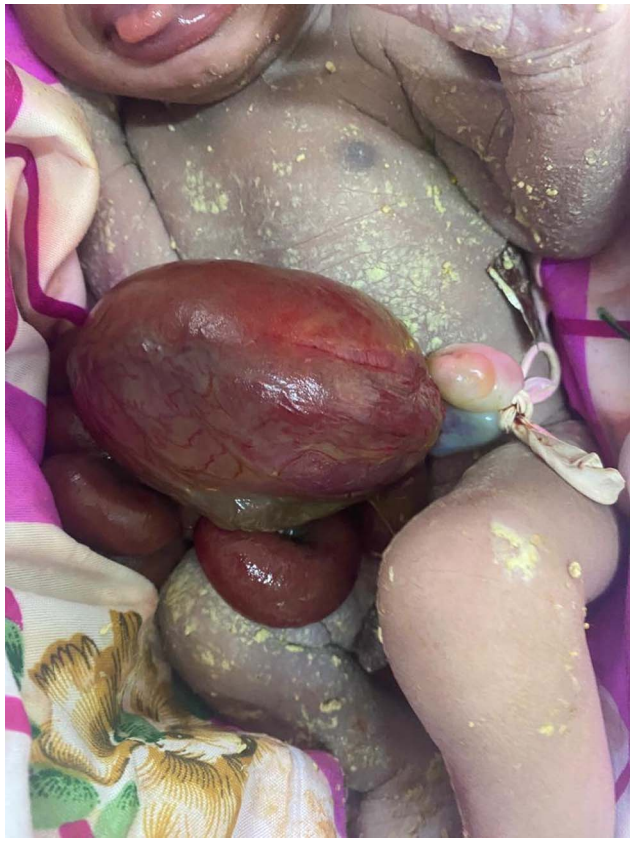

Figure 1. Term neonate with gastroschisis.

Case management, surgical outcomes, and associated challenges

Pre-referral supportive care

After delivery at the lower health centre (level three), the attending midwife considered an immediate referral to the nearby hospital (regional referral hospital) but the referral was marred with delays of up to 6 h without any first aid and treatment. Health workers in lower health facilities in Uganda and other developing countries lack adequate knowledge and skills to manage cases of abdominal wall defects[11] and health facilities lack the necessary equipment and ambulances to organize and effect the immediate transfer of patients to a tertiary hospital[12].

After 6 h of delayed care, the mother and caretaker travelled by public transport (taxi) and managed to reach the regional hospital where the neonate was stabilized on an infant warmer and managed conservatively before the next referral for surgical repair.

Placing bowel bag

At the regional referral hospital, the attending physician and his surgical team immediately put the abdominal bowel and viscera in a bag improvised from a urinary catheter after covering the viscera with wet sterile saline gauze. This is because the hospital does not stock modern bowel bags and so tried to use a modified silo technique (see Fig. 2).

Figure 2. Bowel and viscera covered in bowel bag (silo) improvised from urinary catheter bag.

Feeding and rehydration

A nasogastric tube was placed initially to decongest the stomach, and the neonate placed on Nil Per Os (NPO), and intravenous fluids (dextrose 10% in Normal Saline) were given at 60 ml per kg per day until transfer/referral (~3 h).

Routine neonate care

Immunization for BCG, Polio, and Hepatitis was performed; tetracycline eye ointment (TEO) administered to both eyes; intramuscular vitamin K (1mg stat) given, while umbilical cord, and the skin were cleansed with saline water.

Prophylactic antibiotics and ART initiation

Intravenous ampicillin at 50 mg/kg/day and gentamycin at 5 mg/kg/day were given. This baby was a "high risk" infant for HIV infection since the mother was never on highly active anti-retroviral therapy (HAART) until delivery time and so it was started on HIV prophylaxis (oral daily Nevirapine for 12 weeks) and the mother started HAART based on national HIV treatment guidelines[13].

Patient education and referral

The condition of the neonate and possible available treatment options and outcomes, including referral for surgical repair, were explained to the parents after stabilizing the baby.

Tertiary surgical repair and outcomes

On arrival at the primary hospital, the neonate remained on supportive care for over 12 h and was then referred again to a tertiary national referral hospital after stabilization. The free ambulance system at the regional referral hospital was non-functional at the time of referral so it was up to the patient's family to mobilize resources to manage the transfer to the tertiary surgical centre. In this case, the neonate reached the tertiary referral facility (Mulago National Referral Hospital) on day 3 of life (72 h after birth) due to delays in transportation, where it was scheduled for emergency surgical repair.

Compared to remote health facilities, neonatal services at the National Referral Hospital are well established with adequate neonatal intensive care unit including respiratory support and theatres for gastroschisis repairs. The neonate was urgently attended to upon arrival and immediate surgical repair was sanctioned. Under general anaesthesia, a sub-umbilical midline incision was made to enlarge the abdominal wall defect, and non-necrotic protruding abdominal viscera was placed into the abdominal cavity. The remaining swollen protruding viscera was placed in a newly created pouch made from the urinary catheter bag to cover and protect the abdominal viscera using the modified silo technique[10].

Upon follow-up, there was marked necrosis of the exposed viscera and sepsis of parts of the exposed viscera and incision wound. Although the attending surgeon had prescribed twice daily dressing, it was found that the nursing team could dress the abdominal wound once per day and this increased the risk for sepsis. On day 5 of life, the protruding abdominal viscera was matted and necrotized and the neonatal condition complicated to severe sepsis (focal septic incision wound and abdominal viscera), parenteral nutrition was not possible even at this highest level of care and the neonate died on day 7 of life from hypovolemic shock while awaiting secondary abdominal closure of the abdominal wall defect at the hospital.

Discussion

This is a case report of an HIV-exposed low-birth-weight neonate whose mother had no folic acid supplementation during the first trimester, diagnosed with gastroschisis presenting with bowel and stomach protrusion from the abdominal wall defect at birth. Diagnosis of gastroschisis is often apparent at birth; however, prenatal diagnosis is also possible within an advanced care setting through an ultrasound scan finding of a floating bowel in the second trimester (usually around 20 weeks of gestation) and a positive maternal serum alpha-fetoprotein[1,6,7]. Diagnosis in this neonate was made at delivery since obstetric ultrasonography was not performed during antenatal care attendance.

No other structural congenital abnormalities were observed on the full neonatal physical examination (head-to-toe systemic examinations) other than intrauterine growth restriction (weight for height z-score less than negative 3SD) found during anthropometric measurements, a common finding in neonates with gastroschisis[4,6]. Children with congenital abnormalities can be syndromic, and the presence of gastroschisis may suggest the presence of another anomaly[1,7]. Ten percent of neonates diagnosed with gastroschisis have associated abnormalities outside the gastrointestinal tract[1,6], commonly congenital heart and

neuro-tube defects; however, no other structural congenital abnormalities were identified in this neonate.

Periconceptional folic acid supplementation within 12 weeks of gestation prevents infants from developing congenital birth defects[14,15]. In this case, the mother was initiated on folic acid late, around 16 weeks of gestation, which could have increased the risk of abdominal wall defects in the neonate. There was no sufficient history to establish any familial and environmental teratogenic exposures, nor was the neonate born premature, but the mother's occupation was peasant farming, lived in a rural setting during the pregnancy period, and hence could have been exposed to environmental teratogens such as pesticides, which most studies have associated with gastroschisis[1,2,4,7]. In addition, the neonate was born to a 19-year-old mother, which increases the risk of acquiring an abdominal birth defect. In a population-based study in California, it was found that the risk of gastroschisis decreased with advancing maternal age compared with maternal age below 20 years[2]. The neonate was also born to an HIV-positive mother not receiving HAART treatment throughout the pregnancy period, putting the neonate at high risk of mother-to-child HIV transmission, which increased the risk of gastroschisis in this infant[16].

Gastroschisis treatment mainly involves surgical closure of the defect to return the exposed bowel and organs into the abdominal cavity. Gastroschisis repair can be a primary or delayed closure, with significant differences in the length of stay, time to enteral feeds, or ventilator time[6,9,10,17]. Management should begin in the delivery room by placing the lower part of the neonate into the bowel bag while initiating maintenance fluids, to reduce evaporative fluid loss through the exposed bowel[6]. However, this is not always possible in low-resource settings with low birth preparedness structures, especially when pregnant women miss maternal alpha-fetoprotein screening and antenatal scans; hence, gastroschisis cannot be predicted. In this case, the diagnosis was only possible at the time of delivery in a peripheral lower-level health facility, followed by two simultaneous referrals to a remote hospital and a tertiary paediatric surgical centre. This caused delays of greater than 72 h for a properly modified silo to be established, which increased the risk of fluid loss, necrosis of the bowel, and mortality[10,17]. This neonate underwent secondary repair with delayed reduction, but unfortunately, we lost the neonate to hypovolemic shock on day 5 of life at the hospital.

Mortality rates among neonates born with gastroschisis are as low as 9% in developed countries and often among babies born with associated congenital heart malformations and prematurity[1,18] but are as high as 30–100% in sub-Saharan Africa due to late presentation and intervention, absence of parenteral feeding modalities, non-functional neonatal intensive care units, and paediatric ventilators[17]. Evidence shows that neonates born with gastroschisis suffer few long-term complications, and surgical repair has good outcomes[6,9,19]; however, this neonate had a high risk of mortality, such as low birth weight, delays in surgical repair (up to 72 h of life), lack of parenteral nutrition, and non-functional neonatal intensive care unit encountered in the management; however, the neonate died of hypovolemic and septic shock on day 5 of life.

Patient education on the neonate's condition, including possible risk factors for gastroschisis, what can be done to prevent the condition in the subsequent pregnancy, available treatment options, and prognosis were discussed with the parents of the neonate, as this is important to alleviate parents' anxiety about the condition of the baby and the outcome of surgery[19].

Recommendations and lessons learnt

This case of gastroschisis shows how the diagnosis and management of neonates born with major congenital structural abnormalities in resource-limited settings is still desirable because of the lack of sophisticated medical care services to assist in early detection during pregnancy and early surgical intervention at birth to prevent associated mortality.

The management of abdominal wall defects requires preventive, promotive, and curative approaches, therefore, a detailed history is needed to identify risk factors for abdominal wall defects, utilize the available cheap and affordable preventive measures, such as administering periconceptional folic acid to all pregnant women, conduct a third-trimester obstetric scan, and have a birth preparedness plan with anticipation for clinical emergencies associated with major congenital abnormalities.

Considering the challenges in the management of congenital abnormalities like gastroschisis in resource-limited settings, healthcare systems should leverage increasing accessibility of early detection of congenital abnormalities through antenatal screening methods, such as obstetric ultrasound and maternal serum alpha-fetoprotein testing to ensure early detection. Preventive strategies for gastroschisis should go beyond early detection but also address known risk factors for example the mandatory antenatal testing of HIV of all pregnant women in Uganda that aims to prevent mother-to-child HIV transmission[16] and availability of pre-conceptional folic acid at the community level[14,20].

The existing neonatal treatment guidelines and protocols in Uganda and World Health Organization Newborn Care Recommendations are general and do not precisely describe the management, and nursing care of neonates born with congenital birth defects like Gastroschisis[12,20,21]. Availing such strategies and protocols can enhance birth preparedness and facilitate timely emergency interventions for neonates with congenital abnormalities[12,22], given the limitations in resources and access to sophisticated medical services.

Peripheral health facilities and primary hospitals lack adequate basic neonatal care equipment, and referral facilities like ambulances and healthcare workers lack the knowledge and skills to manage congenital abdominal wall defects[11,12]. To improve pre-referral management of neonates born with gastroschisis and other congenital abnormal wall defects, there is a need to equip lower-level health facilities with basic resuscitation equipment and zip bags used in the modified silo technique while health workers who work with pregnant women and neonates should undergo basic training in the initial newborn resuscitation techniques and use of zip bags or preparation of modified silo technique[22]. This is crucial particularly for primary hospitals as non-medical challenges often arise during referrals to tertiary hospitals.

As described in the case, there were significant delays in the management and referral of the neonate from the peripheral health facility to reaching the tertiary referral hospital (72 h after birth) which were mainly due to the poor emergency and absence of ambulance services. There is a need to streamline the referral system and address system gaps like the lack of an ambulance

system to minimize transportation delays for neonates requiring specialized care in remote settings. Since most abnormal wall defects are visible and easy to diagnose at birth, quick transportation to a tertiary surgical centre that is well equipped with newborn resuscitation, intensive care unit facilities, competent neonatal surgeons, and nurses can significantly reduce mortality due to these defects.

Parents and relatives of neonates born with congenital abnormalities face considerable social and economic challenges, particularly in resource-limited settings that include stigma, discrimination, lack of social care, and lack of rehabilitation services in the community and while seeking healthcare[23–25]. Therefore, healthcare providers should enhance parental education and support to help parents cope with the diagnosis, understand risk factors, and make informed decisions about the care and treatment options for neonates with conditions like gastroschisis.

Ministry of Health Uganda through its supportive supervision mechanisms[21,22,26] has considered knowledge and skills transfer to general surgeons in primary hospitals through technical support and mentorships by paediatric surgeons. Paediatric surgeons from the national referral hospital travel, and demonstrate surgical skills like inserting a modified silo for Gastroschisis[11] and reconstruction surgeries for other paediatric congenital structural anomalies like spina bifida and cleft lip and palate to the general surgeons that work in resource-limited settings where sophisticated surgical interventions are challenging[22,26,27]. There is hope that with such innovations there will be a reduction in the number of neonates referred to the national referral hospital and also neonates shall receive necessary surgical repairs and proper nursing care immediately and within the nearest referral hospitals.

All in all, there are high neonatal mortality and morbidity rates from gastroschisis and other congenital birth defects in sub-Saharan Africa[5,12,18], therefore, Governments through health ministries need to deliberately invest or lobby for support from partners to improve neonatal intensive care units and ventilator infrastructures including equipping them with the necessary equipment and human resources such as the deployment of intensive care nurses and physicians to improve survival outcomes for infants with congenital structural abnormalities. With the support of partners, the Uganda Ministry of Health launched a 5-million-dollar 5-year national strategic plan in 2022[26,28] to enhance paediatric surgery with a focus on expanding access to services for paediatric surgery and developing tertiary units to manage complicated cases. The plan also includes equipping theatres and training personnel expected to run these facilities.

Methods

This work has been reported in line with the SCARE 2023 criteria[29].

Consent

Written informed consent was obtained from the patient to publish this case report and accompanying images. A copy of the written consent is available for review by the Editor-in-Chief of this journal on request.

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Not applicable.

Author contribution

All authors made significant contributions to the case report. M.T. and F.M.A. contributed to conceptualization, data curation, supervision, validation, visualization, and writing—original draft, and writing—review and editing while W.I.E., S.T. and J.K. did manuscript validation, visualization and writing—review and editing.

Conflicts of interest disclosure

The authors report no conflicts of interest.

Research registration unique identifying number (UIN)

Not applicable.

Guarantor

Munanura Turyasiima (corresponding author) accept the full responsibility for the work and/or conduct of the study.

Data availability statement

The authors confirm that the data supporting the findings of this case report are available in the case report and its supplementary materials.

Provenance and peer review

There is no invitation of peer reviewers.

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