BMJ Global Health

A survey of Ugandan skilled birth attendants regarding beliefs and management of gastroschisis

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To cite: Eze AN, Adaramola OG, Kyasimire D, *et al*. A survey of Ugandan skilled birth attendants regarding beliefs and management of gastroschisis. *BMJ Glob Health* 2026;**11**:e020167. doi:10.1136/bmjgh-2025-020167

Handling editor Barnabas Alayande

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/bmjgh-2025-020167).

Received 14 April 2025
Accepted 17 February 2026

Check for updates

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ABSTRACT

Introduction Gastroschisis mortality is disproportionately high in Africa due in part to delayed presentation and limited surgical capacity. Skilled birth attendants (SBAs) are often the first to encounter these babies and can be an important part of their stabilisation. We assessed baseline Ugandan SBA knowledge of gastroschisis and interest in a training course.

Methods Southwestern Ugandan SBAs were surveyed regarding practice patterns, common beliefs and training course interest. Data were analysed with descriptive statistics.

Results We recruited 121 participants (70 midwives, 51 nurses). Most had a certificate or diploma (n=117, 97%) and 85% had more than 3 years of experience (n=103). Eighty-seven (72%) SBAs had cared for babies with gastroschisis. Most reported that communities stigmatised families (n=67, 55%), saw the child as cursed (n=74, 61%), blamed the mother (n=69, 57%) and advised parents to kill (n=30, 24%) or abandon the child (n=55, 45%). Barriers to families seeking care included healthcare mistrust (n=3, 2%), hopelessness (n=37, 31%), lack of knowledge (n=51, 42%), transportation difficulties (n=54, 45%) and fear of impoverishment (n=84, 69%). Most SBAs were unsure of the cause of gastroschisis and only 6% (n=8) recognised fetal vascular interruption as the cause. While 57% (n=69) prioritised intestinal coverage, only 7% (n=9) and 5% (n=6) would place a nasogastric tube or fast the baby. Three midwives encouraged immediate breastfeeding. Antibiotics (n=22, 18%) and fluid resuscitation (n=19, 16%) were sometimes recommended. Most participants (n=119, 98%) desired a course on gastroschisis management, but 41% (n=50) reported time constraints as a barrier.

Conclusions Southwestern Ugandan SBAs encounter gastroschisis babies, have limited training in its management and desire a training course. Engaging SBAs into a task-sharing role on delivery is a promising next step. Additional studies will be needed to determine if this can improve gastroschisis survival by reducing delays in care and improving community awareness.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is a significant disparity in survival rates of babies born with gastroschisis in high-income countries (96%) versus low-income and middle-income countries (less than 10%).
⇒ In Uganda, babies with gastroschisis have delayed presentation (greater than 6 hours) to referral hospitals which contributes to mortality. In general, there is no prenatal diagnosis, and skilled birth attendants are the first medical providers to encounter these babies.

WHAT THIS STUDY ADDS

⇒ Southwestern Ugandan skilled birth attendants have clinical experience with gastroschisis, but lack formal training regarding management, and have an overwhelming interest to engage as first-responders.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Inviting skilled birth attendants into a task-sharing role immediately on delivery may improve gastroschisis survival by reducing delays in care and improving community awareness.

INTRODUCTION

Gastroschisis is a surgically correctable condition. However, a significant gastroschisis outcome disparity exists between high-income countries (HICs) and low-income and middle-income countries (LMICs). 96% of babies with gastroschisis in HICs survive and live normal lives, while survival is less than 10% in LMICs.[1–5] For babies with gastroschisis, delays in care hinder bowel viability and increase mortality.[5] In Uganda, a country of 21 million children, about 17% of neonatal surgical admissions are due to gastroschisis, but there are only twelve paediatric surgeons who are mostly concentrated in the nation's capital, Kampala.[5–7] Southwestern Uganda, a mostly rural region, has only one paediatric surgeon. Other barriers to survival include a lack of total parenteral nutrition (TPN) and central venous catheters, expensive silos, delays in presentation and lack of neonatology support.[5]

Recognising the impact of these barriers, our group has previously engaged in a series of efforts to reduce gastroschisis mortality in Uganda. We have shown that gastroschisis mortality in Uganda can be reduced from 98% to 58% through implementation of a local treatment protocol that includes an improvised silo (a urine collection bag sewn to the abdominal wall).[1] Recognising that the commercially available silos are too expensive (US$240) for most families, and the locally improvised silo is not ideal, we have developed a low-cost (<US$2), locally constructed silo that is pending Ugandan regulatory approval.[8 9] However, previous work has shown that most babies present to a paediatric surgeon 10–48 hours after birth, at which time they are dehydrated and the bowel inflamed, increasing mortality.[5]

Ugandan skilled birth attendants (SBAs: nurses and midwives) are the first point of contact for most Ugandan babies as 73% of babies are born under the care of an SBA, while 25% are born at home before presenting to an SBA.[10] Unlike paediatric surgeons, there are 70 167 registered nurses and midwives widely distributed in Uganda.[11 12] Recognising the unique position of Ugandan SBAs, we aim to reduce gastroschisis mortality through a task-sharing approach. Initial management of gastroschisis should include warming and fasting the baby, placing a nasogastric tube (NGT) for intestinal decompression, fluid resuscitation, antibiotic administration, bowel coverage, parental education and urgent referral to paediatric surgery.[1] SBAs may be able to initiate key components of this time-sensitive care immediately on delivery and expedite transport to a tertiary hospital with a paediatric surgeon. In this study, we aimed to evaluate the perspectives and baseline knowledge of SBAs regarding gastroschisis and their interest in gaining supplemental training for a larger role in caring for babies with gastroschisis.

METHODS

As the only government hospital in southwestern Uganda with a fellowship-trained paediatric surgeon, Mbarara Regional Referral Hospital (MRRH) receives patients from southwestern Uganda and neighbouring countries such as the Democratic Republic of Congo.

Survey questions were developed for this study in partnership between Ugandan and US colleagues, and SBAs at MRRH reviewed them for cultural appropriateness and relevance prior to deployment (online supplemental appendix A). SBAs who deliver babies in southwestern Uganda were older than 20 years of age and were registered with the Uganda Nurses and Midwives Council and were recruited using network sampling.[13] The study team travelled to several districts and administered the survey at breakrooms in health facilities where the SBAs were employed, to avoid SBA travel expenses. To ensure that the study did not interfere with SBAs' work schedules, participation was scheduled at least 2–3 weeks in advance, and administrative clearance was obtained from each participating health facility. Participation in the study was voluntary and confidential with written informed consent.

With the help of local research assistants, participants completed an electronic survey assessing their baseline knowledge and familiarity with gastroschisis, their interest in participating in a future training course and barriers to participation. The survey also contained questions regarding participant demographics, current management practices, provider out-of-pocket expenses incurred in caring for patients, barriers families face in seeking care, and the community's perspective regarding gastroschisis. Responses included multiple choice and free text options. All surveys were completed in English and a local research assistant was available to assist with translation as needed. As is required by the Ugandan Institutional Review Board, all participants received monetary compensation for study participation of US$5. All data were entered locally on an encrypted and password-protected laptop computer and then uploaded to a REDCap database hosted at Duke University, to which Ugandan and US study personnel all have access.[14 15]

Participant characteristics were summarised. Monetary values were reported in Ugandan Shillings (UGX) and converted to US dollars ($) using an exchange rate of US$1=UGX3720.[16] Descriptive statistics were performed with categorical variables reported as frequencies with percentages, and continuous variables reported as medians with IQRs or means with SD depending on data normality distribution. Group comparisons of midwife vs nurse demographics and survey responses were performed for participant occupation using the χ^2 test for categorical variables. P<0.05 was considered significant. Statistical analyses were performed using Stata, V.18.0 (Stata). Quotations from free responses were reported when they provided important context to the study findings.

RESULTS

In the period of 23 May 2024–5 June 2024, 123 SBAs were recruited. No SBA declined to take the survey, but two SBAs did not complete the survey, leaving a total of 121 participants including 70 midwives (58%) and 51 nurses (42%) (table 1). SBAs were predominantly female (n=101, 83%, p<0.001) and the only male SBAs (n=20, 39%) were nurses.

Of the 121 participants, 97% (n=117) had a certificate or diploma. Only nurses held an advanced degree in the form of a bachelor's (n=3, 2%) or graduate level degree (n=1, 1%). Most (n=73, 61%) SBAs earned 800K–1.5 million UGX (US$215–US$403) per month. Most SBAs spoke English (n=108, 89%) and Runyankole (n=64, 53%) fluently. 85% (n=103) had practised as SBAs for 4 years or more, caring for at least 10 babies per month (n=92, 76%). 72% (n=87) had cared for one or more babies with gastroschisis during their career.

Table 1 Participant demographics and practice patterns

	Midwives N=70 (58%)	Nurses N=51 (42%)	Total N=121	P value
Gender				**<0.001**
Female	70 (100%)	31 (61%)	101 (83%)	
Male	0 (0%)	20 (39%)	20 (39%)	
Median age (years) (Q1 Q3)	30 (28 36)	33 (27 37)	32 (28 37)	0.446
Level of education				0.058
Certificate/diploma	70 (100%)	47 (92%)	117 (97%)	
Bachelor's degree	0 (0%)	3 (6%)	3 (2%)	
Graduate degree (Masters, PhD)	0 (0%)	1 (2%)	1 (1%)	
Languages spoken				
English	63 (90%)	45 (88%)	108 (89%)	0.757
Lunyankore or Runyankole	35 (50%)	29 (57%)	64 (53%)	0.455
Other languages	46 (66%)	31 (61%)	77 (64%)	0.578
Marital status				0.419
Married	49 (70%)	34 (67%)	83 (69%)	
Single	18 (26%)	17 (33%)	35 (29%)	
Divorced/separated	2 (3%)	0 (0%)	2 (2%)	
Living with partner	1 (1%)	0 (0%)	1 (1%)	
Monthly income (UGX)				0.150
<200K (<US$53)	0 (0%)	1 (2%)	1 (1%)	
200K–400K (US$53–US$108)	7 (10%)	3 (6%)	10 (8%)	
400K–600K (US$108–US$161)	9 (13%)	4 (8%)	13 (11%)	
600K–800K (US$161–US$215)	2 (3%)	7 (14%)	9 (7%)	
800K–1M (US$215–US$268)	24 (34%)	13 (25%)	37 (31%)	
1 M–1.5M (US$268–US$403)	23 (33%)	13 (25%)	36 (30%)	
>1.5M (>US$403)	5 (7%)	10 (20%)	15 (12%)	
Number of years of practice				0.461
<1	1 (1%)	0 (0%)	1 (1%)	
1–3	9 (13%)	8 (16%)	17 (14%)	
4–10	34 (49%)	18 (35%)	52 (43%)	
10–20	21 (30%)	22 (43%)	43 (36%)	
>20	5 (7%)	3 (6%)	8 (7%)	
Number of babies delivered in the past month				0.340
<10	14 (20%)	15 (29%)	29 (24%)	
11–20	18 (26%)	12 (24%)	30 (25%)	
21–49	26 (37%)	12 (24%)	38 (31%)	
50–100	8 (11%)	10 (20%)	18 (15%)	
>100	4 (6%)	2 (4%)	6 (5%)	
Number of gastroschisis babies ever encountered in their career				0.269
0	17 (24%)	17 (33%)	34 (28%)	
1–3	40 (57%)	28 (55%)	68 (56%)	
4–6	8 (11%)	1 (2%)	9 (7%)	
7–10	2 (3%)	1 (2%)	3 (2%)	
>10	3 (4%)	4 (8%)	7 (6%)	

Continued

Table 1 Continued

	Midwives N=70 (58%)	Nurses N=51 (42%)	Total N=121	P value

Bolded p-values indicate statistical significance.
UGX, Ugandan Shillings.

SBAs worked in 23 health facilities consisting of 4 level III health centres (15 SBAs), 6 level IV health centres (29 SBAs), 11 general hospitals (51 SBAs) and 2 regional referral hospitals (26 SBAs). They received patients from districts throughout southwestern Uganda and some from eastern Uganda (figure 1).

Most SBAs perceived that babies and their families were believed to be cursed (n=74, 61%) and stigmatised (n=67, 55%). The mother was often blamed (n=69, 57%) for seeing an omen, committing a taboo or infidelity, or not attending antenatal care. SBAs reported that the community often advised parents to abandon (n=55, 45%) or kill the child (n=30, 24%). They reported that the community believed seeking care is futile (n=55, 45%) and would lead to financial toxicity (n=3, 2%) (figure 2A). When asked about why families may decline to seek care, SBAs perceived fear of impoverishment (n=84, 69%), difficulty obtaining transportation (n=54, 45%), lack of knowledge about gastroschisis (n=51, 42%), hopelessness (n=37, 31%), the impact of cultural beliefs (n=35, 29%), difficult access to the few and distant paediatric surgeons (n=31, 26%), fear of stigma (n=23, 19%), lack of family support (n=16, 13%), lack of another caregiver at home (n=14, 12%) and healthcare mistrust (n=3, 2%) (figure 2B).

Many SBAs said they were unsure about the cause of gastroschisis (n=71, 59%), while some cited certain medications (n=54, 45%), exposure to smoking (n=45, 37%), alcohol (n=43, 36%), imaging radiation (n=25, 21%), insufficient folic acid intake (n=24, 20%), herbal remedies (n=23, 19%), maternal malnutrition (n=20, 17%), young maternal age (n=9, 7%), illicit drugs (n=5, 4%) and industrial toxins (n=3, 2%) as risk factors (figure 3A). Significantly more nurses than midwives cited oral contraceptive use as a risk factor (nurse: n=13, 25%; midwife: n=8, 11%; p=0.044). Only 6% (n=8) of SBAs recognised that gastroschisis is caused by a vascular accident and some SBAs believed in spiritual causes (n=10, 8%). One nurse (1%) believed that gastroschisis was caused by iatrogenic injury during a caesarean section, advanced maternal age (n=1, 1%), infidelity (n=1, 1%) or out-of-wedlock pregnancy (n=1, 1%).

SBAs identified a spectrum of potential causes of death from gastroschisis including sepsis (n=104, 86%),

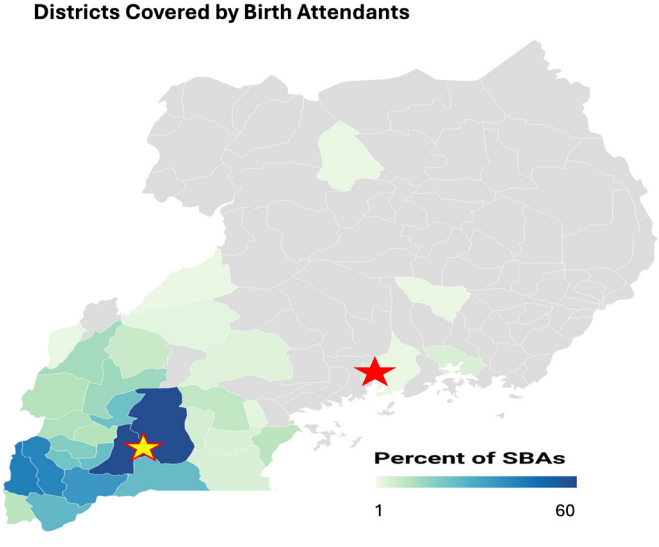


Figure 1 Heat maps of Uganda showing districts covered by SBA participants. The yellow star represents Mbarara Regional Referral Hospital and the red star represents Mulago National Referral Hospital, the only two government hospitals with paediatric surgery services. SBAs, skilled birth attendants.

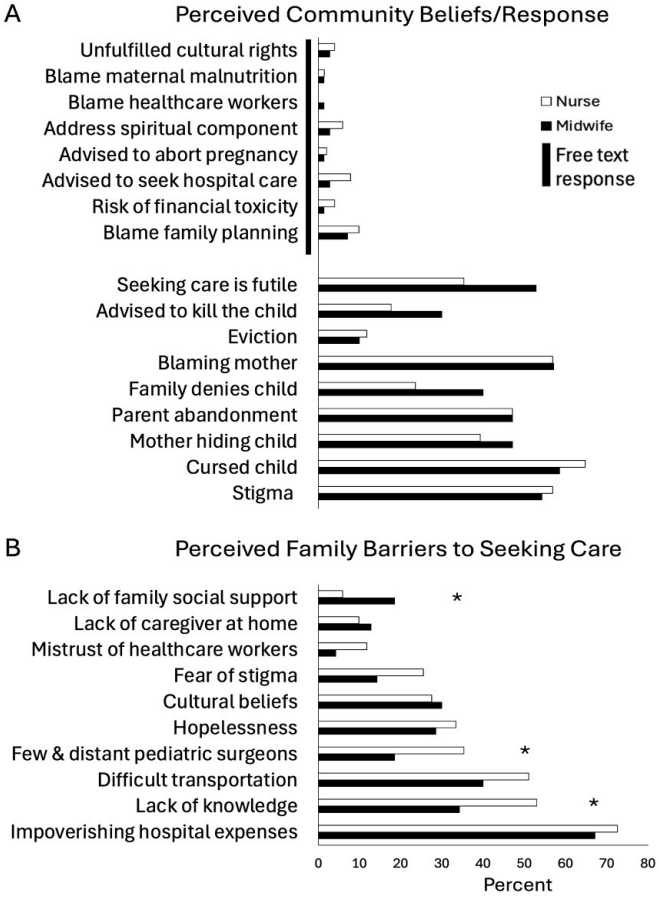


Figure 2 Perceived community responses to gastroschisis. (A) Perceived community beliefs. (B) Perceived family barriers to seeking care. *Designate significant differences between midwives and nurses.

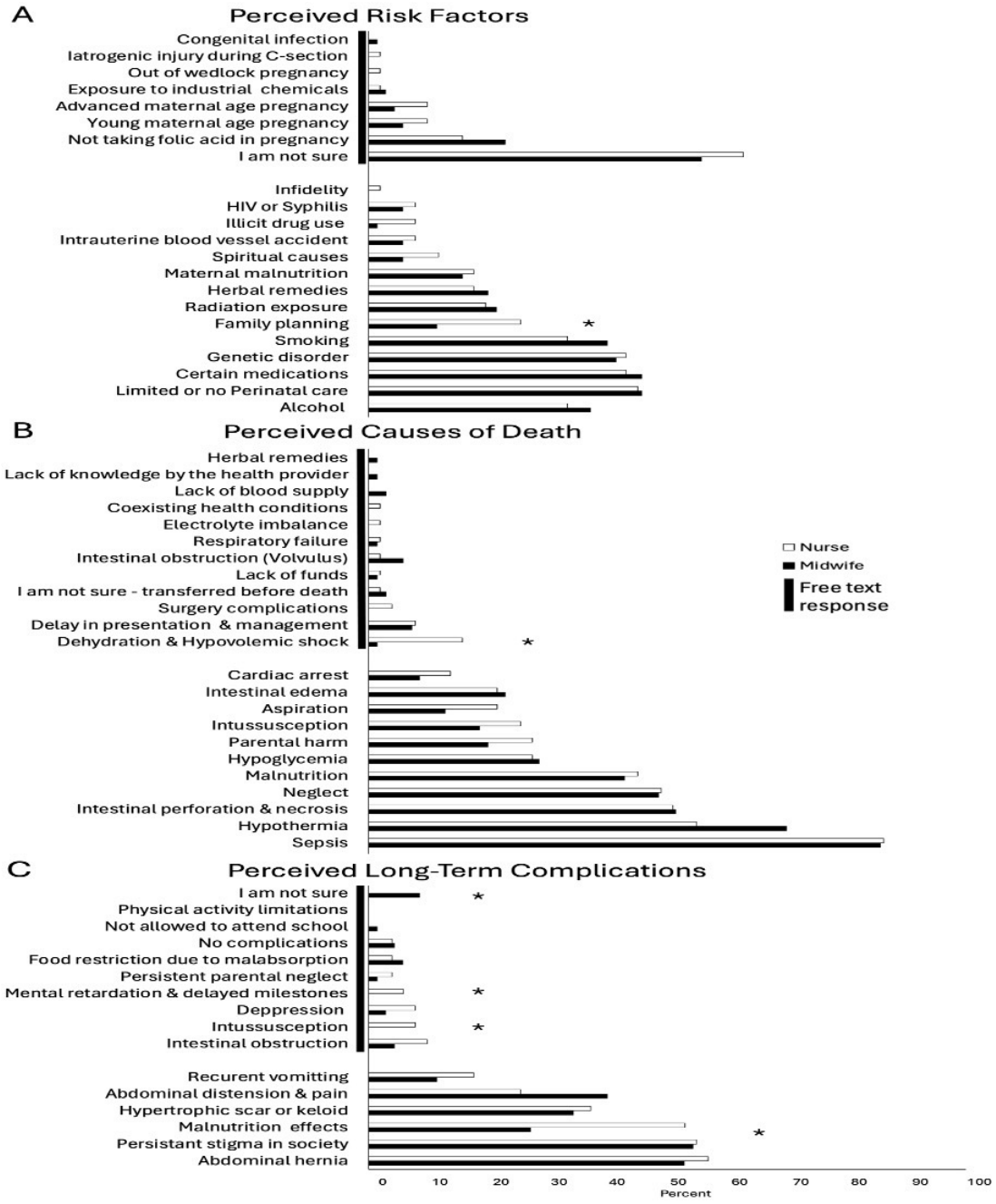


Figure 3 Skilled birth attendants' perceptions of gastroschisis. (A) Perceived risk factors of gastroschisis. (B) Perceived causes of gastroschisis mortality. (C) Perceived long-term complications of gastroschisis. *Designate significant differences between midwives and nurses.

hypothermia (n=77, 64%), intestinal perforation (n=62, 51%), neglect (n=59, 49%), hypoglycaemia (n=34, 28%) and parental harm (n=28, 23%) (figure 3B). Significantly more nurses than midwives recognised that dehydration and hypovolaemic shock (nurse: n=8, 16%; midwife: n=1, 1%; p=0.003) could lead to death.

While 72% of SBAs (n=87) believe that survivors live a normal life, some believed they were at risk of long-term complications like abdominal hernia (n=66, 55%), hypertrophic scars (n=43, 36%), abdominal distention and pain (n=41, 34%) and recurrent vomiting (n=17, 14%). SBAs perceived survivors would face persistent stigma in society (n=66, 55%) manifesting in various ways such as limiting future marriage prospects and parental neglect (n=3, 2%) (figure 3C). One midwife (1%) thought that survivors would not be allowed to attend school. Significantly more nurses than midwives stated that survivors were at risk of intussusception (nurse: n=4, 8%; midwife: n=0, 0%; p=0.017), mental retardation with delayed milestones (nurse: n=3, 6%; midwife: n=0, 0%; p=0.04) and malnutrition related complications (nurse: n=27, 53%; midwife: n=19, 27%; p=0.004).

SBAs were asked about their current practice (figure 4A). 57% (n=69) reported applying a moist

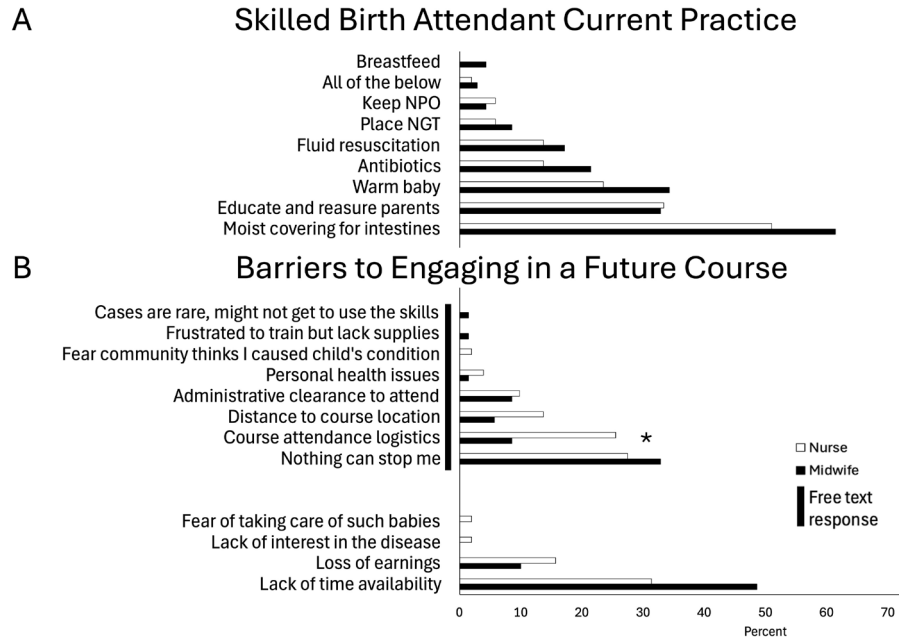


Figure 4 Skilled birth attendant: current and future engagement. (A) Skilled birth attendant current gastroschisis management practices. (B) Barriers to engaging in future supplemental training. *Designate significant differences between midwives and nurses. NGT, nasogastric tube; NPO, *nil per os* "nothing by mouth".

covering to the intestines including moist polythene bag, urine collection bag and even gauze or cotton. 33% (n=40) reported educating the parents. Some SBAs kept the baby warm (n=36, 30%), administered antibiotics (n=22, 18%), initiated fluid resuscitation (n=19, 16%), placed a NGT (n=9, 7%) and fasted the baby (n=6, 5%). Only 2% (n=3) of SBAs reported implementing all the above components of initial management. Three midwives (2%) reported encouraging immediate breastfeeding. Because of frequent national supply shortages and parental financial challenges, 42% of SBAs (n=51) reported using their own money to buy supplies including medications (n=28, 23%), gloves (n=25, 21%), baby clothes (n=17, 14%), intravenous fluids (n=10, 8%), gauze (n=9, 7%), suture (n=8, 7%), NGTs (n=3, 2%), food (n=3, 2%) and sanitary pads (n=1, 1%).

Despite prior experience with gastroschisis, only 7% (n=8) of SBAs reported confidence providing initial care without help, and 13% (n=16) said they would not attempt to manage such babies. After providing initial care, SBAs reported referring patients to higher-level hospitals across Uganda, such as MRRH (n=108, 89%), Mulago National Referral Hospital (MNRH) (n=43, 36%), Holy Innocent Children's Hospital (n=29, 24%), Kabale Regional Referral Hospital (n=14, 12%), Masaka Regional Referral Hospital (n=9, 7%), Mbale Regional Referral Hospital (n=9, 7%) and Jinja Regional Referral Hospital (n=8, 7%). Four SBAs (3%) gave parents money to pay for transportation.

98% of SBAs (n=119) desired training on gastroschisis management. While 31% (n=37) of SBAs stated, 'nothing can stop me', others voiced potential barriers to taking a course (figure 4B). The most frequently reported barriers were lack of time availability (n=50, 41%), loss of earnings (n=15, 12%), distance to course location (n=11, 9%) and administrative clearance to attend (n=11, 9%). Significantly more nurses than midwives reported transportation costs, money for course registration, course materials and personal upkeep while away from home as barriers to course participation (nurse: n=13, 25%; midwife: n=6, 9%; p=0.012). Other barriers cited by nurses were a lack of interest in the disease (n=1, 2%), fear of taking care of such babies (n=1, 2%), 'fear the community thinks I caused the child's condition' (n=1, 2%), 'concern that I might not use the skills due to case rarity' (n=1, 2%) and 'I will be frustrated if I trained but lack the supplies I need to care for the baby' (n=1, 2%).

Through administering the survey, we discovered that at least 15 SBAs (12%) mistook a paediatrician for a paediatric surgeon and did not know to which health facilities patients should be referred. In general, the SBAs demonstrated concern for these patients, as demonstrated by the following response:

> Even though we do not encounter this condition daily, when you do, especially at night when you are the only one on duty, it can be frightening and cause a lot of panic. How are you going to manage it? We really have to fight to make sure we save a life…. But we need more training beyond the brief introduction we got in school. We want to get that training for it, get more knowledge and skills and more updates about its management. This would really improve on our service delivery and our skills to the people out here.

DISCUSSION

In this survey study, we learnt about the perceptions of Southwestern Ugandan nurses and midwives regarding the treatment of gastroschisis and the perceived

community response to these babies. There is a perception that these babies, and subsequently their mothers, are stigmatised by the community. The causes of gastroschisis are not well understood, and there are perceived barriers to seeking care. Midwives and nurses have similar baseline knowledge and experience with gastroschisis, and many educational opportunities exist. Most SBAs reported a care paradigm that contained both correct and incorrect clinical interventions. There is an interest among SBAs to engage in additional training on gastroschisis management, and some SBAs emphasised that potential barriers to participation in a future course may include time, loss of earnings, travel concerns and administrative clearance to attend.

Task-sharing has been successfully adopted by many LMICs to overcome health worker shortages.[17–20] Previous studies have engaged midwives and nurses in sub-Saharan Africa as task-sharers in family planning, health education, antenatal attendance and postnatal care.[21 22] Current evidence suggests that these efforts can improve access to maternal and child health services without compromising patient outcomes, but SBAs must be provided with training, supervision and incentives to support their practice.[23] SBA education has previously been employed in Uganda to improve the prenatal diagnosis of congenital malformations, including gastroschisis.[24] A similar task-sharing approach was recently implemented in Tanzania.[2]

SBAs: a bridge to the community

Ugandan health facilities are predominantly staffed by nurses and midwives who make up 75% of the workforce.[11 12] At the time of this study in 2024, there were 10 paediatric surgeons, located only in Mbarara and Kampala. Given the scarcity of paediatric surgeons, not every health provider knows where these surgeons are located and often patients are sent from one health facility to another in search of the right specialist. Through administering the survey, we learnt that some SBAs often mistook a paediatrician for a paediatric surgeon. This may result in patients being referred to the wrong regional referral centre, increasing delays and travel expenses. Educating SBAs regarding the appropriate specialist type and where these specialists are located would help families to navigate more efficiently through the health system.

It was perceived that cultural beliefs influence the community's response to babies with gastroschisis. Our results highlight that SBAs are the first point of contact for many babies with gastroschisis, and at least 72% of SBAs in our study had cared for babies with gastroschisis. SBAs are uniquely positioned to serve as a bridge with the mostly rural community of southwestern Uganda, as all participants lived within the community, belonged to the tribal groups and most were proficient in English and a native language. Some participants spoke five languages. Many SBAs paid for medical supplies with their own money, and some gave money to parents for transportation to referral centres. SBAs have influence in the community and if empowered, may be able to effect change in cultural perceptions and decision-making.[25 26]

Educational opportunities

Current evidence suggests that gastroschisis is caused by an in utero vascular accident, and risk factors include young maternal age, smoking, alcohol use, illicit drug use, genitourinary infections, malnutrition and certain medications.[27 28] However, only a few SBAs in our study recognised that gastroschisis is caused by a vascular accident during pregnancy. Some believed that gastroschisis has spiritual causes and one nurse believed that gastroschisis was due to iatrogenic injury during a Caesarean section. Many SBAs demonstrated knowledge of known risk factors such as young maternal age, smoking and alcohol use.[27 29–31] However, some SBAs also thought that advanced maternal age, infidelity and out-of-wedlock pregnancy cause gastroschisis. While SBAs recognised that exposure to certain medications is a risk factor, they reported a wide array of medications, some of which are not supported by literature.[29 32–35]

Gastroschisis is rarely associated with other anomalies, and survivors generally live normal lives.[3 34] Approximately 5% may require additional abdominal surgery later in life, and one-third have chronic constipation.[36] However, in Uganda, the initial mortality is high, and therefore few older survivors exist. In our study, 72% of SBAs believed that survivors of gastroschisis can live a normal life. However, participants thought that even after full recovery, survivors may face persistent parental neglect and stigma in society, affecting various aspects of their lives such as marriage potential and school attendance. Some nurses believed that survivors would experience mental retardation or delayed milestones. If survival from gastroschisis can be increased, then perhaps more babies will be observed living normally into adulthood. This experiential knowledge is important for both SBAs and community members so that false beliefs can dissipate and they can be motivated to care for the baby and to educate the community.

Prior to transferring a baby with gastroschisis to a paediatric surgeon, initial stabilisation of the infant and at least preliminary education of the parents should be performed. This can reduce the drivers of gastroschisis mortality.[5] At the time of this survey, many SBAs were implementing some aspects of an initial care package (warming, placement of a NGT, fasting, administration of antibiotics, fluid resuscitation and bowel protection), but only 2% reported implementing all elements. Unfortunately, three midwives encouraged the mother to immediately breastfeed, which can increase the risk of aspiration. While it was encouraging to see that most participants covered the exposed abdominal contents, some reported using gauze or cotton, which can stick to the bowel, increasing inflammation and the risk of perforation. While some SBAs reported using a urine collection bag or colostomy bag, no one reported using a silo.

Silos are not supplied to government health facilities and are not locally available for purchase.[5 8] Finally, only one-third of our participants reported educating and reassuring parents and stated that they would require further knowledge to do so.

Limited training in gastroschisis is not restricted to our nursing participants in Uganda. In high-income settings, most babies will receive a prenatal diagnosis and will be advised for delivery in a tertiary care centre with paediatric surgical resources.[37] Thus, nurses and midwives are not left unsupported to manage these patients in HICs. In Uganda, paediatric surgery resources are in short supply, and there are many educational opportunities to empower SBAs to provide initial management and education.

Commitment to service and supplemental training

While medical care is free in Ugandan government hospitals, families frequently shoulder out-of-pocket expenses for supplies that are not provided.[38 39] Silos, neonatal-sized NGTs, central lines and TPN are not included in the government supply and are rarely available for purchase in private facilities. Some medications such as antibiotics are purchased by the health system in limited supply and others are not available, necessitating that families purchase these supplies out-of-pocket. Even though SBAs in this study made 800K–1.5 million UGX (US$215–US$403) per month, many SBAs reported using their own money to buy supplies for patients.

SBAs are very motivated to learn, with 98% of our participants indicating a desire for supplemental training in gastroschisis management. There were very few participants who reported a lack of interest in the disease, fear of caring for such babies or concern that the cases are too rare and they might not use the skills. Nearly one-third of SBAs stated that nothing would stop them from participating in a future course.

Next steps: implementation of a gastroschisis course

This study revealed important barriers to participation in a future course such as work schedule conflicts, loss of earnings, lack of administrative clearance, registration cost, travel time and travel expenses. SBAs also mentioned fear that the community may think that they are responsible for the baby's condition and potential frustration of having skills while lacking supplies. These are very important barriers that we addressed during the development of a training course that will be described in a future publication. Briefly, we recommend the following considerations:

- Notify participants several weeks in advance to arrange for time away from work.
- Consider providing monetary compensation and travel reimbursement.
- Provide multiple in-person training sites to minimise travel for participants.
- Engage with health facility leadership to facilitate administrative clearance for participants.
- Provide course content that includes education in gastroschisis aetiology and treatment, with a special focus on respectfully addressing local myths.
- Construct educational posters that will serve as a lasting reminder of the main teaching points and clinical pathways.
- If funding allows, provide midwives with silos and NGTs.
- Partner with local paediatric surgeons; this will encourage multidisciplinary relationships and establish referral patterns.

Study limitations

While this study has provided valuable insight into the perspectives of SBAs in southwestern Uganda, this study is not without limitations. Study participants were recruited via network sampling, which is vulnerable to selection bias. This was a survey study and is vulnerable to recall bias. Gastroschisis is a rare condition and SBAs may report inaccurate memories if their experience was traumatic or occurred long ago. The survey nature of the study may also be devoid of some contextual nuances that are not easily depicted through a survey, such as certain components of stigma unknown to us. We have combatted this by also conducting interviews with nurses and midwives, the results of which will be published in a separate article. There were two SBAs who did not complete the survey and were excluded from analysis, as they did not answer enough questions to provide useful data. Additionally, while we endeavoured to get a broad sample of SBAs in southwestern Uganda, this sample may not be generalisable to other regions in Uganda. This survey was conducted with a small number of SBAs, as there are over 70 000 nurses and midwives registered with the Uganda Nurses and Midwives Council.[11 12]

CONCLUSIONS

Southwestern Ugandan nurses and midwives have similar baseline knowledge and experience with gastroschisis, but many educational opportunities exist. There is an overwhelming interest among SBAs to engage in additional training on gastroschisis management. As the first point of contact for babies born with gastroschisis, SBAs are uniquely positioned to provide timely care, as they are deeply committed to their patients and their community. They have influence in the community and if empowered, may be able to effect change in cultural perceptions and decision-making. Additional training and clinical research will be needed to determine if engaging SBAs into a task-sharing role can improve gastroschisis survival by reducing delays in care and improving community awareness.

Contributors ANE created the project, obtained IRB approval and funding, performed data collection and analysis and drafted the manuscript. OK and WSH performed statistical analysis and manuscript editing. OGA, DK, GA and INN performed data collection and manuscript editing. SB performed project planning and manuscript editing. FO coordinated IRB approval, oversaw project execution and edited the manuscript. TNF created the project, coordinated IRB approval,

obtained funding and oversaw project execution and manuscript drafting. TNF is the guarantor for this work.

Funding This research was supported by the 2024 AAS/AASF Global Surgery Research Fellowship Award and funds from the Hubert Yeargan Center at Duke University.

Disclaimer The funders did not influence the results/outcomes of the study despite author affiliations with the funder.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study was approved by the Institutional Review Boards of Mbarara University of Science and Technology (MUST-2023-1207), the Uganda National Council for Science and Technology (HS3270ES) and Duke University (Pro00114298). Participation in this study was voluntary, confidential and each participant provided a signed informed consent. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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Author note The Reflexivity Statement for this paper is linked as an online supplemental file 2.

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