



Mortality among newborns with neural tube defects at the Kinshasa University Hospital, Democratic Republic of Congo

Mortalité Chez les nouveau-nés avec troubles de fermeture du tube neural aux Cliniques Universitaires de Kinshasa, République Démocratique du Congo

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Summary

Context and objective. Since September 2023, the Democratic Republic of Congo (DRC) has implemented Universal Health Coverage (UHC) with free care for newborns. This has increased the number of newborns admitted in Kinshasa University Hospital (KUH), particularly those with neural tube defects (NTD). The present study was conducted to determine the mortality rate of newborns referred for NTD. **Methods.** A case series was conducted at the KUH and involved newborns admitted for NTD from January to December 2024, whether operated on or not. Pearson's Chi-square and Student's t tests were used to compare proportions and means, respectively. **Results.** The 32 newborns with NTD were distributed into 23 cases of myelomeningocele (71.9%) and 9 cases of meningoencephalocele (28.1%). Fifty percent of the mothers completed their pregnancies without any obstetric ultrasound. The antenatal diagnosis rate was 6.2%. Eleven newborns (34.3%) died. For 8 of them (72.7%), no surgical procedure was performed or considered. The remaining 3 (27.3%) died postoperatively. **Conclusion.** Despite improved access to care for newborns with NTD, neonatal mortality is very high, especially in the preoperative period. Preventive measures for NTD must be implemented to reduce their prevalence and mortality rate.

Keywords: Neural tube defect, neonatal mortality, Kinshasa, Democratic Republic of Congo

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Résumé

Contexte et objectif. Depuis Septembre 2023, la République Démocratique du Congo (RDC) a lancé la Couverture Santé Universelle (CSU) avec des soins gratuits aux nouveau-nés. Ceci a favorisé l'affluence des nouveau-nés aux Cliniques Universitaires de Kinshasa (CUK) et en particulier ceux avec troubles de fermeture du tube neural (TFTN). La présente étude a été menée pour déterminer le taux de mortalité des nouveau-nés transférés pour TFTN. **Méthodes.** Il s'agissait d'une série des cas conduite aux CUK. Elle a concerné les nouveau-nés admis de janvier à décembre 2024 pour TFTN, opérés ou pas. Les tests de Chi-Carré de Pearson et t de Student ont été utilisés pour comparer respectivement les proportions et les moyennes. **Résultats.** Les 32 nouveau-nés avec TFTN étaient répartis en 23 cas de myéломéningocèles (71,9%) et 9 cas de méningo-encéphalocèles (28,1%). Cinquante pourcents des mères sont arrivées au terme de leurs grossesses sans aucune échographie obstétricale. Le taux de diagnostic anténatal était de 6,2%. Onze nouveau-nés (34,3%) sont décédés. Pour 8 d'entre eux (72,7%), aucune intervention chirurgicale n'a été réalisée ou envisagée. Les 3 restants (27,3%) sont décédés en postopératoire. **Conclusion.** Malgré l'amélioration de l'accessibilité aux soins, la mortalité néonatale est très élevée surtout en période pré-opératoire. Des mesures de prévention des TFTN doivent être mises sur pied pour diminuer leur prévalence et le taux de mortalité.

Mots-clés : Troubles de fermeture du tube neural, mortalité néonatale, Kinshasa, République Démocratique du Congo

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Introduction

Neural tube defects (NTDs) are a group of congenital malformations secondary to a neurulation defect during the fourth week of embryonic life (1). Anencephaly, myelomeningocele and meningoencephalocele are the most frequently reported (2-3). The prevalence of NTDs varies across different regions of the world and ranges from 1 to 10 per 1,000 live births (1, 3-4).

Their etiopathogenesis remains complex and includes both genetic and environmental factors (4-5). In some countries where folic acid-based preventive measures have been instituted, the prevalence of these malformations has declined significantly (6-9). Each year, NTDs are responsible for 88,000 deaths worldwide. According to some studies (9-10), NTDs are responsible for 29% of neonatal mortality in resource-limited countries where 75% of affected children die before their fifth birthday.

In the Democratic Republic of Congo (DRC) where some studies on congenital malformations report a predominance of NTD (11-12), their prevalence has not yet been determined. At the University Clinics of Kinshasa, the annual frequency of NTD seems increasing (from 6 cases in 2010 to 17 cases in 2022).

Since September 2023, our country has launched Universal Health Coverage with free care for newborns. This has encouraged the influx of newborns into our hospital, particularly those with NTD. These newborns are generally born and transferred in poor conditions because of the lack of antenatal diagnosis. This study was conducted to determine the mortality rate of newborns transferred for NTD.

Methods

Design, period and setting

This study is a case series conducted from January to December 2024 at the Kinshasa University Hospital. It involved newborns admitted to the neonatology unit for neural tube defects, whether operated on or not. Data were retrospectively extracted from medical records and patient charts.

Parameters of interest

The following parameters of interest were sought: For both parents: age, alcohol use, smoking history, diabetes mellitus in the family, family history of NTD or other congenital malformation;

For the mother: folic acid use in periconceptional period, diabetes mellitus, fever in the first trimester of pregnancy, spontaneous abortion or stillbirth, parity, and obstetric sonography.

For the newborn: age at admission, sex, birth weight, type of NTD, surgical procedure performed, preoperative and postoperative course, immediate cause of death.

Statistical Analysis

Data were entered into Excel 2013 and exported to SPSS for Windows version 22 (IC Chicago) for analysis. Results were expressed as the mean plus the standard deviation for Gaussian-distributed data, as the median plus the interquartile range (IQR) for non-Gaussian-distributed data, and as the absolute or relative frequency for categorical data. Pearson's Chi-square and Student's t tests were used to compare proportions and means, respectively. The statistical significance level was set at 5%.

Ethical consideration

Confidentiality and anonymity were respected. Our work received approval from the Ethics Committee of the School of Public Health of the University of Kinshasa under number ESP/CE/021/2024.



Results

General characteristics

Of a total of 121 newborns transferred to CUK for surgical pathology, 32 (26.4%) presented with TFTN (Table 1). Each of fourteen newborns (11.6%) presented one of the following pathologies: cervical abscess, amniotic bands of the left lower limb, necrotizing fasciitis of the

trunk, wet gangrene of the left arm, dry gangrene of the left arm, cystic lymphangioma of the right forearm, arteriovenous malformation of the left thigh, right jugal mass, nasal mass, phimosis, rectal polyp, hypertrophic pyloric stenosis, testicular torsion, mesoblastic nephroma).

Table 1. Main surgical pathologies received during the study period

Pathology	N=121 (%)
Neural tube defect	32 (26.4)
Anorectal malformation	21 (17.4)
Laparoschisis	12 (9.9)
Neonatal bowel obstruction	10 (8.3)
Acute generalized peritonitis	8 (6.6)
Omphalocele	6 (4.9)
Esophageal atresia	5 (4.1)
Inguinoscrotal hernia	5 (4.1)
Hydrocephalus	4 (3.3)
Bladder exstrophy	2 (1.7)
Prune Belly Syndrome	2 (1.7)
Others	14 (11.6)

The 32 cases of NTD were divided into 23 myelomeningoceles (71.9%), 9 meningoencephaloceles (28.1%). The sex ratio was 1.13. The majority of newborns (59.4%) were admitted on the day of birth, 12.5% on the second day, 12.5% on the third day, and 28.1% beyond the third day.

Nine mothers (28.1%) reported a history of spontaneous abortion. In seven of these, the spontaneous abortion immediately preceded the

pregnancy affected by NTD. The majority of mothers had started antenatal care (ANC) beyond the first trimester of pregnancy. Fifty percent of mothers completed their pregnancies without any obstetric ultrasound. Antenatal diagnosis was made for two cases of meningoencephalocele. For myelomeningoceles, no antenatal diagnosis was made. The sociodemographic and clinical data of the parents are presented in Table 2.

Table 2. Parents' sociodemographic and clinical data

Characteristics	Father n=32 (%)	Mother n=32 (%)	P
Mean age (Years)	36.12 ± 8.012	26.81 ± 5.294	< 0.0001
Alcohol use	17 (53.1)	9 (28.1)	< 0.0001
Tabac history	4 (12.5)	0	
Family history of diabetes mellitus	3 (9.3)	2 (6.2)	
Family history of malformation	0	0	
Level of education			< 0.0001
Unkown or under secondary	7 (21.9)	11 (34.3)	
Secondary	15 (46.9)	20 (62.5)	
University	10 (31.2)	1 (3.2)	
Profession			< 0.0001
Official	11 (34.4)	1 (3.1)	
Liberal	14 (43.8)	13 (40.6)	
Others (no occupation, household, student)	7 (21.8)	18 (56.3)	
Folic acid use in periconceptional period		0	



Fever in the first trimester of pregnancy	13 (40.6)
History of spontaneous abortion	9 (28.1)
History of stillbirth	0
Parity	
Parity 1	13 (40.6)
Parity 2-3	10 (31.2)
Parity 4-7	9 (28.1)
Beginning of antenatal care	
First trimester	7 (21.8)
Second trimester	23 (71.8)
Third trimester	2 (6.2)
No antenatal care	1 (3.1)
Obstetrical sonography	
First trimester	7 (21.8)
Second trimester	12 (37.5)
Third trimester	11 (34.3)
None	16 (50.0)
Antenatal diagnosis	2 (6.2)

Surgical procedures performed

Among the 32 newborns, 24 underwent surgery (75.0%). The median time between admission to surgical procedure was 25 days with an interquartile range of 17. These were 20 cases of myelomeningocele (83.3%) and 4 cases of

meningoencephalocele (16.7%). The procedures performed on the newborns are presented in Table 3. Simultaneous MMC treatment with ventriculoperitoneal shunt (VPS) was the most performed surgical procedure.

Table 3. Procedures performed on newborns

Procedures performed	n=24	%
Meningo-encephalocele treatment		
Alone	3	12.5
With simultaneous VPS	1	4.2
Myelomeningocele treatment		
Alone	5	20.8
With delayed VPS	2	8.4
With Simultaneous VPS	11	45.7
After interval VPS	2	8.4

Mortality

Eleven of thirty-two newborns (34.3%) died (Table 4). For 8 of them (72.7%), no surgical procedure was performed or considered. Of the 24 newborns operated on, three newborns (12.5%)

died. These were newborns in whom simultaneous MMC treatment and VPS were performed. The first newborn died on the fourth postoperative day of meningitis and the other two of respiratory distress after two weeks.

Table 4. Preoperative and postoperative mortality

	MMC n=6	MEC n=5	Total n=11
Preoperative death			
Therapeutic	0	3	3
Abstention			
Meningitis	1	0	1
Respiratory distress	2	2	4
Postoperative death			
Meningitis	1	0	1
Respiratory distress	2	0	2

MMC=Myelomeningocele



MEC=meningoencephalocele

Discussion

The primary objective of this study was to determine the mortality rate among newborns with NTD.

Age and sex

More than a third of the newborns were admitted after 48 hours of birth, even though all were born in Kinshasa, with the exception of one of them. This delayed transfer is likely to increase morbidity and mortality, especially for myelomeningocele patients, which constituted nearly three-quarters of our sample. Unlike several studies (13-16), we noted a male predominance. However, this is also reported by some studies (6, 17-18). In their study, Radouani and Tirsit (19-20) noted a balanced sex ratio.

Antenatal diagnosis

This study recorded a low obstetric ultrasound performance rate (50%). For all cases of myelomeningocele, the diagnosis was made at birth. Antenatal diagnosis was made for two out of 8 cases of meningoencephaloceles (25%). Worldwide, most cases of NTD are diagnosed antenatally for both meningoencephaloceles and myelomeningocele (14-16, 21-22). For myelomeningocele, some studies report an antenatal diagnosis rate of one hundred percent (23-24). In addition to raising awareness among pregnant women about antenatal care, training (or retraining) of health professionals should be organized for the antenatal diagnosis of NTD. Appropriate imaging equipment should be made available to health professionals to detect NTD antenatally. Since medical termination of pregnancy for myelomeningocele and meningoencephaloceles is not allowed in our country, an antenatal diagnosis committee should be established to improve the quality of care for newborns with NTD.

Type of NTD

Myelomeningocele constituted the majority of our sample. It is established in the literature that myelomeningocele and anencephaly are the most common NTDs, with proportions varying across the globe. For the majority of studies (16-17, 21-22, 25-26), myelomeningocele is more common than anencephaly, while for some, it is the opposite (19, 27-28). Our sample did not include any cases of anencephaly. Since survival in case of anencephaly is estimated for a few hours to a few

days, some cases would be retained in maternity wards for supportive care.

Mortality among newborns admitted

The overall neonatal mortality rate was 34.3% and the postoperative mortality rate was 12.5%. Before the discharge of newborns admitted for NTD, Mengiste (18) reported a death rate of 8%, while Al-Wassia and Krzesinski (16, 21) reported 33% and 50%, respectively. Five of nine newborns admitted for meningoencephaloceles died. Three of them had part of the ventricular system in the extracranial brain tissue (meningohydroencephalocele). The remaining half presented with respiratory distress that led to death before preoperative medical imaging. Like Bui (29), we did not record any postoperative deaths for meningoencephaloceles. In a selective study of occipital meningoencephaloceles (30), a postoperative death rate of 2% was noted. In another study, a mortality rate of 29% was reported by Kiymaz (31). On 23 newborns with myelomeningocele, six died (26.1%). Both preoperatively and postoperatively, one-third died of meningitis and two-thirds of respiratory distress. The three newborns who died postoperatively were all operated on after 72 hours of life and underwent simultaneous MMC treatment and VPS. The first of them presented triventricular hydrocephalus due to stenosis of the Sylvius aqueduct and lumbar kyphosis opposite the myelomeningocele. He died on the 16th postoperative day of meningitis. The second presented isolated vermian hypoplasia, lesions of posthypoxo-anoxic ischemic leukopathy and was operated on after one week of respiratory instability. He died two weeks later of respiratory distress. The third had biventricular hydrocephalus due to an Arnold Chiari II malformation, staged dysraphism of the thoracic spine; T1, T4, T8 hemivertebrae, staged rib fusion, and a solitary left kidney. He was operated on after eight days of respiratory instability. He also died two weeks later of respiratory distress. In a case series, Tirsit (20) recorded no perioperative deaths. In a study based on an international registry, Bakker (32) noted a mortality rate of 6.9% during the first week of life. In a cohort conducted at two hospitals in Lusaka, Zambia, Reynolds (33) reported a postoperative mortality rate of 7%. The high rate of mortality in this study may be explained by the lack of antenatal diagnosis, the late transfer of



newborns in poor conditions and the surgery performed after 72 hours for myelomeningocele.

Limitations

The small size of this study's sample and the single-center aspect are great limitations.

Conclusion

The frequency of TFTN has increased sharply at the Kinshasa University Hospital. Despite improved access to care, neonatal mortality remains very high, especially in the preoperative period. Measures to prevent NTD (folic acid supplementation during the periconceptional period and/or fortification of staple foods with folic acid) must be implemented to reduce its prevalence. Transferring knowledge and skills to health professionals for antenatal diagnosis and rapid transfer of affected newborns is essential to reduce the mortality rate.

Conflict of interest

Authors declared they have no conflicts of interest

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Authors' contribution

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-Data review and verification: Pierre Zalagile Akilimali

-Manuscript revision: Stéphane Tongo Yanda, Paulin Masendu Kalenga, Thérèse Bakabumvua Biselele, Patrick Mukuna Miteo

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