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The Frequency and Distribution of Neural Tube Defects (NTDs) at Arthur Davison Children Hospital (ADCH), Ndola Zambia

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Abstract: *Summary/Abstract Background*: Neural tube defects (NTDs) are one of the commonest malformations with worldwide prevalence of 1-3 per1000 live births. They are resulted by failure of neural tube to close during neurulation in 21-28 embryonic days and it's a multi-factorial in etiology. Currently in Zambia there is no published data regarding NTDs at Arthur Davison Children Hospital (ADCH). Therefore this study was used to assess the frequency and distribution of NTDs at ADCH and will serve as base line reference for further studies. *Method*: A descriptive retrospective study was conducted to review medical records of children aged 1 day to 5 years who attended ADCH between September 2018 and May 2020. *Results*: During the study period, there were 2365 patients admitted at the health institution. NTDs were present in 52 cases, giving a prevalence of 0.022 thus 22/1000 births congenital anomalies of this kind observed at the institution were identified from October 2018 to May 2020 patients' registers, which constituted the study sample. The sample had more boys (61.5%) than girls (38.5%) female with the majority (78.8%) aged between one day to twenty-eight days. The Majority of the children were from Copperbelt province with 88.5%, while the minority were from Muchinga province (1.9%). However the majority of children were from Ndola district (61.5%) and the minority from Mpika district (1.9%). The study showed that many children (96.2%) presented with Spinal Bifida (SB) and lastly encephalocele (3.8%). Myelomeningocele was the most common type of SB (21.2%). Hydrocephalus was the most common associated anomaly (19.2%) while the least associated anomaly was Microcephaly (3.8). *Conclusion*: The study showed that the majority of children were from Ndola district on the Copperbelt province and most children were admitted between day one and twenty eight days after birth. SB was the most common type of NTDs, and among these, those with myelomeningocele were the majority. Hydrocephalus was the most common associated impairment with majority of patients not undergoing any surgical interventions.

Keywords: Neural Tube Defects, Spinal Bifida, Meningocele, Myelomeningocele, Encephalocele, Zambia

1. Introduction

1.1. Back Ground

Neural Tube Defects (NTDs) are a group of congenital defects of the central nervous system, resulting from failure of the neural tube to close during the first few weeks of foet al development [25] NTDs are classified according to the anatomical structures affected: the cranial structures, anencephaly (major part of the brain is absent) or encephalocele (protrusion out of the skull of sac-like meninges and brain tissue), or the spinal structures (spina bifida), meningocele (sac protrudes out of the spine) or myelomeningocele (sac contains spinal cord and nerves) (Bussuk & Kibar 2009). The defect is classified as closed if skin covers the defect and it is classified as open if skin does not cover the defect. Children with NTDs, especially spina bifida, may survive with lifelong neuromuscular, orthopaedic and sometimes cognitive and language disabilities [30].

Global estimates of birth defects indicate that 7.9 million

children are born with birth defects each year and of these 90%are born in low- and middle-income countries (Christianson, Howson & Modell 2006). Neural tube defects (NTDs) are the second most common group of serious birth defects, following cardiac abnormalities, which result in infant mortality and severe disability [27]. The worldwide incidence of NTDs is estimated to range between 1.0 and 10.0 per 1000 births (Au, Ashley-Koch & Northrup 2010). A systematic literature review on NTDs [33] found that the reported incidence of NTDs varied greatly between and within regions. The regional incidence per 10 000 births was 11.7 in Africa, 21.9 in the Eastern Mediterranean, 9 in Europe, 11.5 in the Americas, 15.8 in South-East Asia and 6.9 in the Western Pacific. In hospital-based retrospective studies, an incidence of 7.5 per 1000 births was reported in Algeria (2004–2006) [12], 3.5/1000 births in Sudan (2003–2004) [5] and 2.2/1000 births in Nigeria (2011–2013) [24]. A retrospective study at a paediatric neurosurgical centre in Kenya (2005–2010) reported the incidence of spina bifida and encephalocele as 3.3/10 000 live births [9]. In Zambia, a retrospective review of congenital anomalies at Arthur Davison Children Hospital (ADH) in Ndola district found CNS congenital anomalies to be the most common (40%) [15]. Hospital based prevalence and incidence rates which are common practice of reporting prevalence and incidence rates in most low and middle income countries may not reflect the actual prevalence. Neural tube defects are reported to cause approximately 88,000 deaths globally (in 2012) and 8.6 million disability adjusted life years [33].

The causes of NTDs are multifactorial, involving complex interactions between genetic and environmental factors, with folic acid deficiency being the major risk factor [29]. Even with the complex nature of the epidemiology of NTDs, advances in research have resulted in evidence based preventive and therapeutic measures against these defects [30].

Preventive measures involve the use of periconceptional folic acid during childbearing years while therapeutic measures involve in utero repair of SB for the unborn child, resulting in significant outcomes for the child [30]. Postnatal management involves surgery to close the lesion immediately after birth, while subsequent surgeries may be required for tethered spinal cord, hydrocephalus and other orthopedic and neurological problems [11].

The advances made in prevention and management of NTDs, African countries still lag behind with most countries experiencing challenges related to prevention and management. Furthermore, the health care services for children with NTDs are often more costly and may not be affordable for most families from developing countries who are mainly from low socioeconomic background [14]. Besides the cost of care involved with NTDS, children in developing countries face many other challenges such as harsh social economic conditions, harmful taboos, religious beliefs, and inadequate medical personnel and facilities, which all lead to late presentation of patients for appropriate health care [13]. Additionally, surgical services in most developing countries are only found in big cities making it difficult for the poor rural communities to access the services [7]. This may result in late presentation for surgery, high mortality rates and severe secondary complications for those who survive [17].

Despite all the challenges associated with management and prevention of NTDs in developing countries, these anomalies are unrecognized and underreported in most sub-Saharan African countries [1]. In Zambia, children who are born with NTDs from any part of the country are supposed to be transported to Lusaka if they require surgical management. This could be because surgical repair and shunting for NTDs is only done in Lusaka at the University Teaching Hospital (UTH) and Beit Cure Hospital, a private hospital. Therefore, the aim of this study is to report on the frequency and pattern of distribution of neural tube defects at ADCH which is the only pediatric hospital in the country located in ndola district on the copperbelt province and serves as a referral hospital for the northern part of Zambia.

1.2. Statement of the Problem

In Zambia, all children born with NTDs and in need of surgery have to be transported to Lusaka for surgical management because specialist surgery is only available at the University Teaching Hospital (UTH) and Beit Cure Hospital, both of which are in Lusaka, the capital city of Zambia [28]. Nevertheless Closure of the open myelomeningocele is advisable within 24 hours, or 48 hours at most, as closure beyond this period results in infection of the defect [26]. To add on there has been no study that has been carried out in the northern part of Zambia only some studies based in Lusaka at UTH, which showed that the most common NTD was spinal bifida and most of the patients were from Lusaka province while the least number of patients were from the Copperbelt province. That's why carrying out this study to determine the frequency and pattern of distribution of neural tube defects at ADH will help provide information, that may help in implementing policies that may bring management of these defects at the doorstep like opening neurosurgery services at the hospital unlike always evacuating patients to Lusaka always and to reduce mortality rate from these defects. Lastly the study may also help in effective sensitization on the importance of taking folic acid by pregnant women and abstaining from factors that may lead to NTDs.

1.3. Objective

1.3.1. General Objective

To determine the frequency and the pattern of distribution of neural tube defects at Arthur Davison Children Hospital (ADH).

1.3.2. Specific Objectives

To determine the prevalence of NTDs.

To determine the distribution of NTDs by age, gender, type, district and province.

To find out the surgical managements used.

To find out associated impairments.

1.4. Statement of Hypothesis

Are NTDs really a burden for the northern part of Zambia?
Which is the most prevalent Neural tube defect at ADCH?
What is the surgical management of NTDs at ADCH?

1.5. Study Justification

Despite the administration of folic acid, there has been incidences of NTDs though no local literature points out the frequency of these defects. In order to make informed interventions and programmatic decisions that will achieve significant reductions in patients with NTDs, local studies are needed. There is a need to describe the burden of NTDs and identify gaps in available NTD data. This study will be conducted to determine the frequency and pattern of distribution of NTDs at ADCH.

1.6. Measurement

File records were collected from the hospital registry of patients aged 0 to 5 years of age admitted to ADCH between 2016 and 2019. This was after a permit was given by the hospital administration.

Table 1. *Measurements.*

Measurements	Distribution
Age	NTDs
Gender	NTDs
Frequency	NTDs
Province	NTDs
District	NTDs
Year of diagnosis	NTDs
Associated impairment	NTDs
Surgical management	NTDs

1.7. Conceptual Frame Work

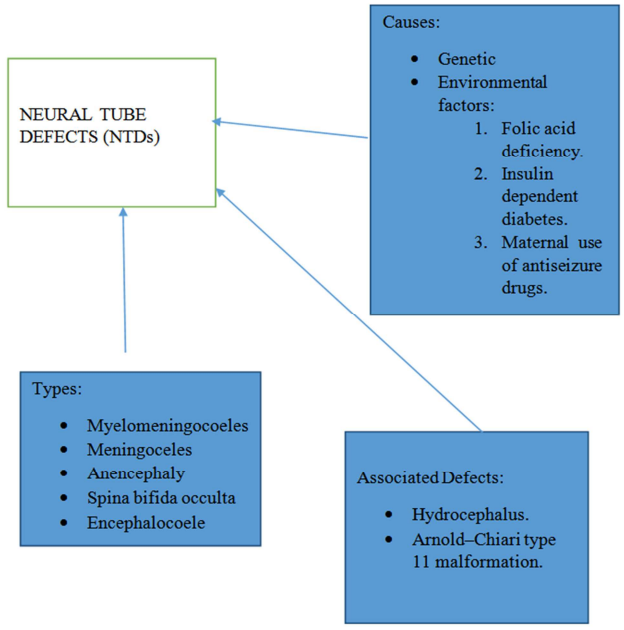

Figure 1. *Conceptual frame work.*

2. Literature Review

2.1. Global Perspective

The term neural tube defect (NTD) is applied to a variety of central nervous system (CNS) abnormalities, most of which result from a lack of closure of the neural tube. Worldwide, the prevalence of NTDs is approximately 1–5/1000 live-births and the risk of recurrence is 2–3% [33].

2.2. Regional Perspective

According to a study carried out in Northwestern Nigeria is showed that there were 10, 163 deliveries and NTDs were present in 22 cases, thus giving a prevalence of 2.2/1000 deliveries. The common types of NTDs were spinal bifida 72.7% (16/22), anencephaly 22.7% (5/22), and encephalocele 4.6%. There was a preponderance of females, with a female to male ratio of 1.4:1. Hydrocephalus was the most common associated anomaly 36.4% (8/22). The mothers were mainly within the age range of 20–35 years 59.1% (13/16), parity 2 or more and of low-socioeconomic n status. Diagnoses were made by antenatal ultrasonography 50% (11/22) and clinically (50%) after delivery. The perinatal mortality was 81.8% (18/22) [24].

In South Africa during a 6-year period 195 NTDs were identified at a Western Cape Province tertiary hospital. These included 59 (30%) cases of anencephaly, 28 (14%) of encephalocele and 108 (55%) of SB. The majority of NTDs (71%) were detected prenatally, although SB was less commonly diagnosed prenatally than cranial defects (56% v. 88%; $p<0.001$). Of SB cases ascertained pre- or postnatally, 57% of patients were born alive and 50% discharged alive, but 72% of survivors had not been diagnosed prenatally. Women receiving prenatal diagnosis of any type of NTD before 24 weeks' gestation were nearly always offered TOP, and the majority accepted termination after non-directive counselling. For SB, later prenatal diagnosis was associated with much lower termination rates because the option was less often offered (51% v. 100%; $p<0.001$), and perhaps less often accepted (57% v. 78%; $p=0.06$). The estimated NTD birth prevalence for the referral arean was 0.76 - 0.80 per 1 000 live births, but perhaps up to 1.18 per 1 000 when considering under-referral of lethal cranial lesions from rural areas [6].

2.3. Local Perspective

In a study on Managing Children with Spinal Bifida in sub-Saharan Africa: the Zambian experience? Foundou Foundouh Majority (56%) of the patients were aged between 1-6 months ($p<0.001$). Hydrocephalus was prevalent in 61% of the patients. Myelomeningocele was the most common (61%) defect and the lumbar region was the common site (60%) ($p<0.001$). Majority (28%) of children came from the Southern Province of Zambia ($p<0.001$). The majority (81%) of patients were lost to follow-up ($p<0.001$). None of the files had outcomes measuring instruments [22].

Another study on Profiling Children with Neural Tube Defects at the University Teaching Hospital, Lusaka, Zambia found a total of 101 patients with NTDs were identified from the 2010 patients' register and out of these, only 50 medical records were located, which constituted the study sample. The sample had more boys (58%) than girls (42%). The majority of the children were from Lusaka province with 28%, while the minority were from North-Western and Copperbelt provinces with 2% each. The profile showed that many children (78%) presented with Spina Bifida (SB), with encephalocele (20%) and lastly one with both SB and encephalocele (2%). Myelomeningocele was the most common type of SB (44%) while the lumbar region was the commonest site (52%). Occipital encephalocele (12%) was the commonest cranial NTD compared with the nasal (6%) and frontal (2%). The majority of the children with NTDs admitted at the UTH were from Lusaka province and SB was the most common type of NTDs. Myelomeningocele was the most common presentation while the lumbar region was the most common site. Occipital encephalocele was the commonest compared with other encephaloceles [28].

3. Methodology

3.1. Study Site

The study was carried out at Arthur Davison Children Hospital, which is the largest Children's referral hospital in Zambia, located in Ndola, the provincial capital for the Copperbelt province of Zambia. It's a tertiary hospital that caters mostly for referrals from the northern region of Zambia which include: Copperbelt, Northwestern, Luapula, Muchinga, Northern, and part of Central provinces of Zambia.

3.2. Target Population

All file records of patients aged between 0 to 5years admitted to ADCH between 2018 to 2020.

3.3. Study Design

This is a descriptive retrospective study, to show the frequency and pattern of distribution of Neural Tube Defects presenting at Arthur Davison Children Hospital.

3.4. Sample Size

The sample size included all patients aged 0 to 5 years admitted to ADCH for NTDs between 2018 and 2020.

3.5. Sampling Procedure

The study population was identified using the ward and theater admission registers. Before data extraction from individual patient's medical records, a list of file numbers and names for all patients who were admitted between 2018 and 2020 was generated from the admission registers. Using the list, a search for individual patient files was conducted.

3.6. Inclusion Criteria

This study included male and female patients aged 0 to 5 years admitted to ADCH between 2018 and 2020.

3.7. Exclusion Criteria

The exclusion criteria included patients above 5 years of age admitted to ADCH.

3.8. Data Collection

Data was collected from patient files from ADCH registry office and a data collection tool was formulated that included; age, gender, province of referral, management of NTD, type of NTD and NTDs versus associated impairments.

3.9. Data Analysis

Analysis was done using Statistical Package for Social Sciences (SPSS) version 16.0. The SPSS version 16.0 was used to process the frequencies and percentages to be used in discussing the findings. Tables, pie charts and bar graphs from Microsoft Excel 2013 will be used to present the data.

3.10. Ethical Consideration

Ethical clearance was sort from Tropical Disease Research Centre and final clearance was granted by the National Health Research Authority (NHRA). Permission to use the data was sort from Ministry of Health and Arthur Davison Children Hospital (ADH) management. Data collected was kept with highest confidentiality and no names only indicators were collected.

4. Results

The results of this study are presented under prevalence, demographic characteristics, type of neural tube defect, associated impairment, surgical management and year of diagnosis.

4.1. Prevalence

During the study period, there were 2365 patients admitted at the health institution. NTDs were present in 52 cases, giving a prevalence of 0.022 thus 22/1000 births congenital anomalies of this kind observed at the institution.

4.2. Sample Demographics

Table 2 shows the distribution of patients according to province of referral. The majority of patients were from Copperbelt province (88.5%). The distribution according to district comprised of 12 districts the highest being Ndola 32 (61.5%). The gender distribution for the study sample was 32 (61.5%) male and 20 (38.5%) female. The age distribution ranged from day 1 to 5 years with the majority (78.8%) aged between one day to twenty-eight days (n=41). Distribution according to year of diagnosis was from 2018 to 2020 with majority of cases in 2019 (48.1%).

Table 2. *Distribution according to province.*

Province	Frequency (n)	Percentage (%)
Copperbelt	46	88.5
Luapula	3	5.8
Muchinga	1	1.9
Northwestern	2	3.8
Total	52	100.0

Table 3. *Distribution according to district.*

District	Frequency (n)	Percentage (%)
Chambishi	1	1.9
Chililabombwe	3	5.8
Chingola	1	1.9
Chipili	1	1.9
Kalulushi	2	3.8
Kitwe	3	5.8
Luanshya	1	1.9
Mansa	2	3.8
Mpika	1	1.9
Mufurila	3	5.8
Ndola	32	61.5
Solwezi	2	3.8
Total	52	100.0

Table 4. *Distribution according to gender.*

Gender	Frequency (n)	Percentage (%)
Female	20	38.5
Male	32	61.5
Total	52	100.0

Table 5. *Distribution according to Age.*

Age	Frequency (n)	Percent (%)
1 to 28 days	41	78.8
1-12 months	10	19.2
1-5years	1	1.9
Total	52	100.0

Table 6. *Distribution according to year of diagnosis.*

Year of diagnosis	Frequency (n)	Percentage (%)
2018	13	25.0
2019	25	48.1
2020	14	26.9
Total	52	100.0

4.3. Types of Neural Tube Defects

The study showed that 50 (96.2%) children with NTDs presented with spinal bifida and 2 (3.8%) with encephalocele. Myelomeningocele was the most common type of the classified spinal bifida with 11 (21.2%) children. The distribution according to type of neural tube defect were summarized in the *Table 7* below.

4.4. Neurological Impairments

The most common neurological impairments recorded in the patients' files where incontinence and paraplegia. From this sample (n=52), the distribution of neurological impairments was as follows: 23 patients had paraplegia, and out of these 15 had incontinence also and one patient had incontinence only. Furthermore, the results showed that 15 patients had no neurological impairments and 13 patients had no records on neurological deficits.

4.5. Associated Impairment

Table 8 Shows the distribution of patients with NTDs that's had associated impairments. The majority of patients with NTDs presented with associated impairments with hydrocephalus being the highest 10 (19.2%) followed by clubfoot 4 (7.7%) and the least being microcephaly 2 (3.8%). However 36 (69.2%) were found not to have any impairments according to the admission registers and the reviewed files.

4.6. Surgical Management

Table 9 shows the distribution of surgical management of patients with NTDs. Surgical management consisted of repair of the defect (34.6%), insertion of a shunt only (0%) or both the repair of the defect and the insertion of a shunt (9.6%) and 53.8% of the children did not undergo any surgical management. The ventriculoperitoneal shunt (VPS) was the type of shunt that was used for all the children who had shunt insertion.

Table 7. *Distribution according to type of neural tube defects.*

Type of neural tube defect	Frequency (n)	Percentage (%)
Unclassified Spina Bifida	32	61.5
Meningocele	7	13.5
Myelomeningocele	11	21.2
Encephalocele	2	3.8
Total	52	100.0

Table 8. *Associated impairments.*

Associated impairment	Frequency (n)	Percentage (%)
No Impairment	36	69.2
Microcephaly	2	3.8
Hydrocephalus	10	19.2
Clubfoot	4	7.7
Total	52	100.0

Table 9. *Distribution according to surgical management.*

Surgical management		Frequency (n)	Percentage (%)
	Defect Repair	18	34.6
	VPS and Repair	5	9.6
	No Surgery	28	53.8
	Total	51	98.1
Missing	System	1	1.9
Total		52	100.0

5. Discussion

The aim of this study was to determine the profile of children with NTDs at a tertiary hospital in Zambia. The study included demographic characteristics, prevalence of NTDs, types of NTDs, site of the NTD, neurological status of the affected children and surgical management.

5.1. Prevalence

The estimated prevalence of NTDs in this study was 22/1000 births, Which was higher than a study conducted at a

South African tertiary hospital in cape town with an estimated prevalence of 1.18 per 1 000 births [6]. The differences could be attributed to the denominator (live-births) used in the previous studies, whereas the population sampled in this included both live and stillbirths. It is however comparable to the African region range of 5.2–75.4; 11.7 per 10,000 births [13] and thus agrees with the observation that reported incidence of NTDs varies from country to country and even with regions in the same country. The high prevalence in this study might be attributed to the short study duration and also during the study period only critical patients were admitted to avoid the spread of CORVID 19.

5.2. Demographic Characteristics

Data on NTDs in developing countries like Zambia is very scanty and where available, it is restricted to hospital based studies. The majority of children in this study where referred from Copperbelt province. However a retrospective review of medical records of children with NTDs who were admitted at the UTH between January and December, 2010 found that the minority of patients were from Northwestern and Copperbelt provinces, Lusaka had the highest number of patients [28]. This could be because the study was conducted in Lusaka province which is in the southern part of Zambia of which Copperbelt province is outside Lusaka, where the study was conducted. In the current study, the high prevalence of children with NTDs was Ndola on the Copperbelt province which could be attributed to geographical accessibility as reported in another study which was done in Cameroon where the majority of the patients (66%) came from within the city of Yaounde where the hospital was based [4]. Geographical accessibility is one of the dimensions of access that has been reported to favour people living in urban areas compared to those living in rural areas [8].

While findings on age at presentation are similar to some studies done in some African countries, there are other studies within Africa whose findings were contrary to this study. Studies reporting similar findings include a one year retrospective review conducted at UTH which reported an age range of one day to one month at presentation [28] and another one year prospective study conducted in a Nigerian neurosurgical unit, which reported the

age at presentation to range from two days to 60 months with a mean age of between 5.8 to 11.47 months [1]. On the contrary, a retrospective medical record review that was done in Cameroon (2000-2006) reported that about 44.13% of children presented on the first day of life with only 7.25% presenting between the first week and fourth week of life [23]. The age on admission for children with NTDs is an important factor in determining the outcome of the management. Surgical closure for open NTDs should be done within 36 to 72 hours after birth to minimize the risk of CNS infection and improve the neurological outcome.

The male predominance in the current study is consistent with findings from another study done in Zambia [28] and other similar studies in some African countries such as Cameroon [7]. Contrary to these findings, other studies done in Africa and other regions have reported female predominance among children with NTDs like a prospective study carried out in northwestern Nigeria on the prevelance of NTDs at Usmanu Danfodiyo University Teaching Hospital, Department of Obstetrics and Gynaecology [24]. There are many theories that are used to explain the gender variations among children with NTDs. One assertion is that female children are more likely to have cranial NTDs than spinal defects [4]. Males [5, 12].

5.3. Type of Neural Tube Defect

Myelomeningocele was the commonest type of spininal bifida with a high prevalence in this study which was also reported in other Zambian studies one was a retrospective study done at UTH and Beit Cure Hospital between 2001and 2010 [22] then another one done at UTH only from January to December 2010 [28]. Other studies done in both African and non-African countries have reported myelomeningocele as the most common type of NTD [23, 18]. Although this study did not report any case of anencephaly, there are other studies which reported more cases of anencephaly than encephalocele in countries such as Texas [18] and Sudan [5] these studies which reported high incidences of anencephaly were characterized by high mortality rates among live births, foetal deaths and abortion rates because anencephaly is incompatible with life. It is for this reason that we cannot rule out the availability of cases of anencephaly in Zambia because most of these children are unlikely to reach tertiary level hospitals.

5.4. Associated Impairments

Hydrocephalus was the commonest associated impairment reported in the current study (19.2%) and was also more associated with myelomeningocele as most patients with this type of NTD had hyrocephalus. These findings are supported by Sinha et al [29] who noted that about 80-90% of children with myelomeningocele have hydrocephalus. Furthermore, [32] observed that about half to two thirds of children with myelomeningocele require treatment for hydrocephalus and about one third of those with encephalocele will require management for hydrocephalus.

5.5. Surgical Management

Surgical management involved closure of the lesion only, shunt only, or both shunt and closure of the lesion and 44.2% of children underwent surgery. The other 55.8% did not undergo any surgical management as most of them who had infected lesions were sent home and their mothers advised to return on given dates. In another study conducted at UTH by [28] 70% children underwent surgery and only 30%. The reason to why most patients didn't undergo surgery in this study might be attributed the CORVID pandemic due to that only emergency surgeries were done during this time especially for 2020 cases. This study did not report on whether the children who had both shunting and closure of

lesion had either staged or simultaneous surgery. Literature on surgical management of children with NTDs indicates that there are variations in the surgical management with some authors supporting simultaneous surgery while others go for staged surgery [23]. According to Margaron and colleagues [19], simultaneous surgery may not be possible for most children in African countries because of the late presentation which is characterized by infected wounds and therefore poses a high risk of shunt malformation.

6. Limitations

Limitations of medical record reviews include missing admission registers, files and details from patient's files for the intended study period. Others included difficulty interpreting or verifying documented information and variability in quality of documentation among health personnel. Corvid 19 affected the accessibility to the health facility both to the researcher and patients as they could only admit patients that needed serious medical attention.

7. Conclusion

The study showed that the majority of children were from Ndola district on the Copperbelt province and most children were admitted between day one and twenty eight days after birth. SB was the most common type of NTDs, and among these, those with myelomeningocele were the majority. Hydrocephalus was the most common associated impairment with majority of patients not undergoing any surgical interventions. The findings from this record review suggest that management of children with NTDs in Zambia is faced with challenges such as late presentation. This is consistent with literature which indicates that developing countries have higher incidences of children with NTDs and yet are faced with many challenges related to prevention and management.

8. Recommendation

The late presentation and majority of patients not receiving surgical intervention indicates the challenges with accessibility of specialty services for children with NTDs in Zambia. In order to improve the health care delivery for these children, there is need for the government to provide transport to these children during first referral as well as follow up management. There is also need of sensitizing the community on the possibility of correcting NTDs in Zambia for children born with such defects and to seek medical attention as soon as possible incase of home delivery which are common in the rural areas. Furthermore, the outcome of patients who are lost to follow up is also not known and therefore there is need for research in this area so as to determine the outcome of these patients.

List of Abbreviations

WHO: World Health Organization NTDs: Neural Tube Defects

ADCH: Arthur Davison Children Hospital UTH: University Teaching Hospital.

Acknowledgements

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Appendix

I. INFORMATION

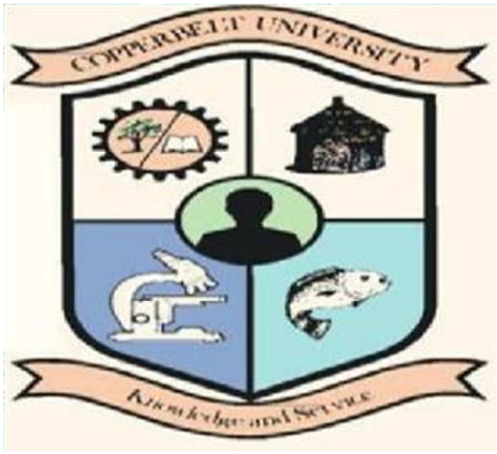


Figure 2. *The Copperbelt University Logo.*

RESEARCH TITLE: The frequency and distribution of Neural Tube Defects (NTDs) at Arthur Davison Children Hospital (ADCH).

LEAD RESEARCHER: Mutambo Poster

LOCALITY: Arthur Davison Children Hospital (ADCH), Ndola district.

SUPERVISOR: Mr P Siapila

ETHICAL COMMITTEE: Tropical Disease Research Centre (TDRC)

1. Gender

Male	Female

2. Age

0 to 28 days	1 to 12 months	1 to 5 years

3. Residential Address

District	Province

4. Year of Diagnosis

2016	2017	2018	2019

5. Type of Neural Tube Defects

6. Management of the Neural Tube Defect

Defect Repair	VPS and Repair	VPS	No surgery

7. Associated Impairment

Missing data	No impairment	Microcephaly	Hydrocephalus with deformities	Hydrocephalus with clubfoot	clubfoot

Figure 3. *Information sheet.*

II. WORK PLAN

The study will run for 24 weeks. Data collection will be done in 8 weeks and the other 18 weeks will be used for data entry, analysis and report writing as illustrated in the time schedule table in the gantt chart below.

Table 10. *Work plan.*

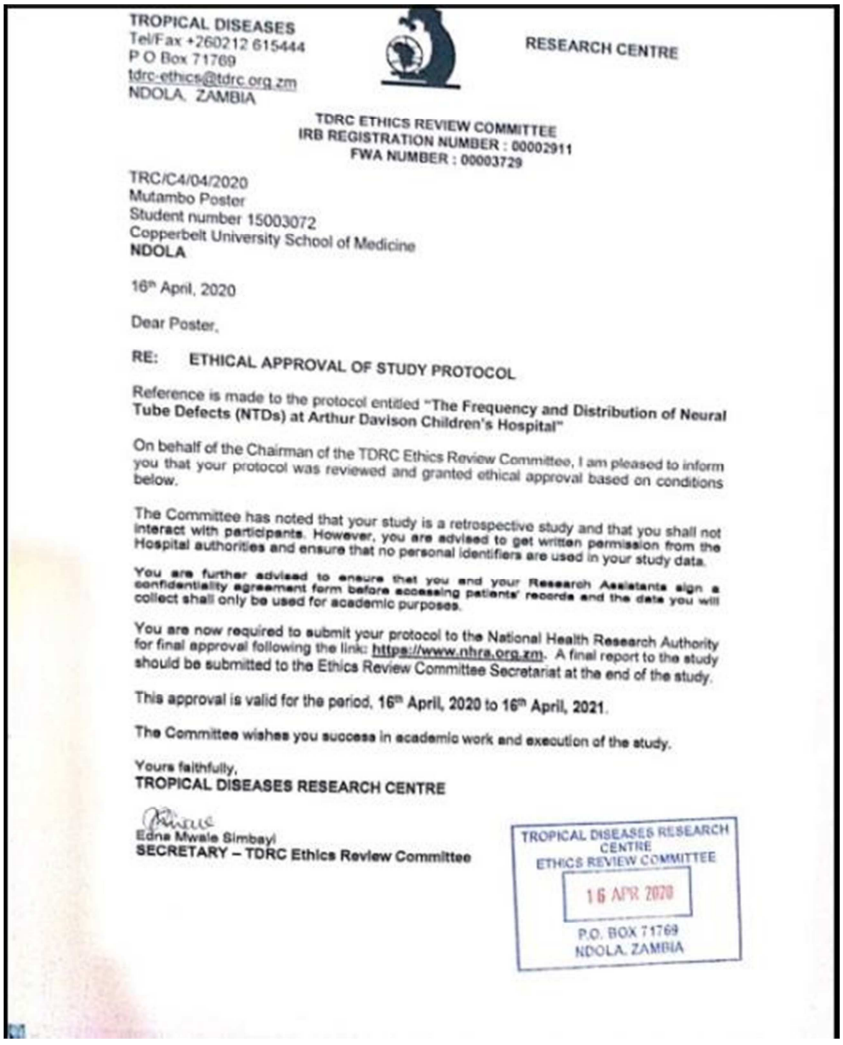
Weeks Action	1-8	9-10	11-12	13-14	15-16	17-18	19-20	21-22	23-24
Ethical approval									
Pilot study and data collection									
Data entry									
Data analysis									
Project report writing									
Submission of Draft report									
Submission of final report									

III. BADGET

Table 11. *Budget*

Stationeries	**K150.00**
Printing + photocopying cost	K500.00
Transportation	K500.00
Refreshments	K600.00
Project binding	K50.00
Miscellaneous	K1,000.00
Ethics clearance fee	K500.00
Research assistant	K300.00
Contingency 5%	
Total	K3,600.00

IV. TDRC ETHICAL APPROVAL LETTER



TROPICAL DISEASES
Tel/Fax +260212 615444
P O Box 71769
tdrc-ethics@tdrc.org.zm
NDOLA, ZAMBIA

RESEARCH CENTRE

TDRC ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER : 00002911
FWA NUMBER : 00003729

TRC/C4/04/2020
Mutambo Poster
Student number 15003072
Copperbelt University School of Medicine
NDOLA

16th April, 2020

Dear Poster,

RE: ETHICAL APPROVAL OF STUDY PROTOCOL

Reference is made to the protocol entitled "The Frequency and Distribution of Neural Tube Defects (NTDs) at Arthur Davison Children's Hospital"

On behalf of the Chairman of the TDRC Ethics Review Committee, I am pleased to inform you that your protocol was reviewed and granted ethical approval based on conditions below.

The Committee has noted that your study is a retrospective study and that you shall not interact with participants. However, you are advised to get written permission from the Hospital authorities and ensure that no personal identifiers are used in your study data.

You are further advised to ensure that you and your Research Assistants sign a confidentiality agreement form before accessing patients' records and the data you will collect shall only be used for academic purposes.

You are now required to submit your protocol to the National Health Research Authority for final approval following the link: https://www.nhra.org.zm. A final report to the study should be submitted to the Ethics Review Committee Secretariat at the end of the study.

This approval is valid for the period, 16th April, 2020 to 16th April, 2021.

The Committee wishes you success in academic work and execution of the study.

Yours faithfully,
TROPICAL DISEASES RESEARCH CENTRE

Edna Mwale Simbayi
SECRETARY – TDRC Ethics Review Committee

TROPICAL DISEASES RESEARCH CENTRE
ETHICS REVIEW COMMITTEE
16 APR 2020
P.O. BOX 71769
NDOLA, ZAMBIA

Figure 4. *Tropical Diseases Research Center Ethical approval Letter.*

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