A cluster of paediatric hydrocephalus in Mohale's Hoek district of Lesotho, 2013-2016

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ABSTRACT

Background: In 2016, an unusual increase of paediatric hydrocephalus was observed in Mohale's Hoek (MH) district, Lesotho. This study describes the epidemiology of paediatric hydrocephalus, and review the management of case-patients in MH district. **Methods:** We defined a case-patient as a child ≤12 years diagnosed with hydrocephalus either radiologically (i.e. by CT or MRI scan) or clinically by a medical officer. We reviewed registries and medical records of children diagnosed or treated with hydrocephalus at national referral hospital in Maseru and in MH district. We also conducted a household survey among case-patients identified in MH. **Results:** A cumulative total of 75 case-patients with paediatric hydrocephalus were identified in Lesotho, giving an overall prevalence of 87/100,000 live births over the 2-years. Thirty-seven (49.3%) were diagnosed with congenital hydrocephalus, and 5 (6.7%) were acquired hydrocephalus post-meningitis. Overall, 11 case-patients were identified in MH district, giving an overall 4-years prevalence of 211/100,000 live births; case fatality of 4/11 (36.4%). The median age at the time of diagnosis was 3 weeks (range: 1 week - 12 months) and five of the 11 case-patients were diagnosed in 2015. Two (18.2%) were diagnosed with congenital hydrocephalus, 2 (18.2%) with acquired hydrocephalus post meningitis and 7 (63.6%) had hydrocephalus of unspecified origin. Five children had shunts inserted in South Africa with an average delay of about 3 months from diagnosis. All five shunts developed complications that resulted in their removal. **Conclusion:** Our findings provided an insight into the burden of hydrocephalus in Lesotho and highlight sub-optimal post-surgery follow-up of children treated for hydrocephalus. We recommend that the Lesotho government implement a national surveillance system for congenital abnormalities and strengthen capacity for neurosurgical procedures at the national hospital.

Introduction

Hydrocephalus - an abnormal accumulation of cerebrospinal fluid (CSF) in the ventricular system of the brain, is the most common paediatric neurosurgical condition in Africa [1–4]. When hydrocephalus develops during early childhood before ossification of the cranial sutures, the elevated intracranial pressure due to excessive build-up of CSF may cause progressive enlargement of the infant's head [1,5]. If treatment is delayed, the child invariably experiences cognitive and intellectual deficits as a result of irreversible injury to the brain and may result in premature death [6–8].

The incidence of congenital hydrocephalus in developed countries is estimated to be between 50-100 per 100,000 live births, while neonatal acquired hydrocephalus is estimated at 30-50 per 100,000 live births [3,6,9]. In most developing countries, the true incidence of congenital hydrocephalus is not known because of the lack of reliable surveillance systems and registries [2,3,9]. However, the incidence or prevalence in developing countries is probably higher due to the existence of risk factors such as nutritional deficiencies, high incidence of perinatal and neonatal infections, and high maternal and perinatal risk factors [2,3].

Hydrocephalus is most commonly treated surgically by inserting a shunt system (ventriculo-peritoneal) to divert the excess CSF away from the cranial cavity, thereby relieving the intracranial pressure and significantly lowering the risk of neurological damage [2,9–11]. However, surgical shunts generally have high rates of failure (e.g. blockage of the shunt) and high risk of post-surgery infections, which may result in serious complications [10,12]. The risk of such complications is elevated if the patients are not adequately monitored and followed up after surgery. Over the past few years' alternative surgical options, such as Endoscopic Third Ventriculostomy (ETV) and Endoscopic Third Ventriculostomy with Choroid Plexus Cauterization (ETV/CPC) have increasingly demonstrated more favourable outcomes [1,2,9,10]. The alternative surgical procedure (ETV/CPC) is potentially more cost-effective especially in resource limited countries. The ETV/CPC procedure generally has lower rates of complications minimizing the costs and complications associated with repeated surgical shunt revisions [2,9]. However, more evaluations on the cost effectiveness of the ETV/CPC are still needed for a conclusive picture.

In June 2016, community health workers from Mohale's Hoek (MH) district of Lesotho notified the Ministry of Health (MoH) in Lesotho of an unusual clustering of cases of hydrocephalus in some parts of the district. The MoH established a national task team to investigate the cluster and make recommendations. The South African Field Epidemiology Training Programme (SAFETP) was invited to support the epidemiological investigation of the cluster. In this paper, we describe the epidemiology of paediatrics hydrocephalus in Lesotho and review the management of case-patients in MH district.

Methods

Study area Lesotho is a Southern African country surrounded entirely by the borders of South Africa. The country has an estimated population of 2.17 million people (projected from 2016 population census). Administratively, it has 80 constituencies distributed across ten districts. Most of the country (>80%) lies above an altitude of 1,800 metres with a largely mountainous terrain, which makes it hard for some communities to access basic healthcare services. Mohale's Hoek (MH) is one of ten administrative districts in Lesotho. The district is located in the South Western region, about 125 km from the administrative capital - Maseru. MH district has an estimated population of 165,590 people (projected from 2016 population census) [13]. MH district is served by one district hospital- Ntseke Hospital and 15 primary level clinics. Queen Mamohato Memorial Hospital (QMMH) located in the capital Maseru, serves as the referral hospital for all the district hospitals in the country. Patients that are diagnosed with clinical hydrocephalus in any of the health facilities in the country are referred to QMMH for further investigation and specialized management. The primary health care clinic is the first point of care in the healthcare system and is manned by professional nurses. Patients with complicated conditions are referred to the district hospital to be evaluated by medical doctors, and then to QMMH if they require specialised investigations or medical care. Patients requiring more specialised services not offered at QMMH are referred to hospitals in neighbouring South Africa. The Lesotho government has a memorandum of understanding

with South Africa regarding the referral of patients for specialised medical care.

Study design

We conducted a retrospective review of medical records of paediatric hydrocephalus patients treated at QMMH and in MH district hospital from 2013 to 2016. Additionally, we surveyed mothers and caregivers of case-patients identified in MH district.

Case definition: We defined a case-patient of paediatric hydrocephalus as a child ≤12 years diagnosed with hydrocephalus either radiologically (by CT or MRI scan), or clinically by a medical doctor either at QMMH or at MH district from 2013 - 2016.

Data collection

Phase 1: Medical records review

To ascertain whether the cluster of hydrocephalus identified in MH district exceeds the expected prevalence, we reviewed medical records of all children treated for hydrocephalus at QMMH from January 2015 to October 2016. We reviewed patient's files, data from the hospital information system, data from the radiology information system, and outpatient department hospital records, to quantify the magnitude of hydrocephalus in Lesotho. The variables we collected included patient name, sex, date of birth, district, admission date and the diagnosis. ==PAR-- At Mohale's Hoek district hospital we reviewed hospital records which included hospital admission registries and patient's files. In addition, we conducted an active search for case-patients in the district's catchment community to identify children diagnosed or treated for hydrocephalus during.

Phase 2: Household survey among cases identified at MH district

The SAFETP resident administered a semi-structured questionnaire to caregivers of case-patients identified in MH district, to collect information such as socio-demographic characteristics, pregnancy, socioeconomic status, available social support, cultural beliefs and practices during and after pregnancy and medical history. We additionally extracted data from the health records of the mother and child that are kept by the patients, commonly referred to as "Bukana". The Bukana is a booklet where medical history and treatment information is recorded each time the patient visits the clinic or hospital.

Data management and analysis

The completed questionnaires were captured in a Microsoft Excel spreadsheet and analysed using STATA 14 (Stata Corporation, College Station, Texas, USA). We conducted descriptive statistics (frequency, percentage, measures of central tendency) of study patients. The prevalence of hydrocephalus was determined as a rate per 100,000 registered live births by number of children ≤12 years who had been treated for hydrocephalus at QMMH and MH district per annual.

Ethical consideration

This investigation was requested and authorised by the Ministry of health (MoH), Lesotho. The South African Field Epidemiology Training Program under the National Institute for Communicable Diseases was cleared by the MoH Lesotho to support the investigation and approved the study protocol. Mothers or care takers were only interviewed after they provided verbal informed consent. Data collected from the participants were de-identified and kept secure.

Results

Socio-demographic characteristics of hydrocephalus cases identified at QMMH

A cumulative total of 75 case-patients ≤12 years with paediatric hydrocephalus were identified from QMMH data registries from 2015 to 2016, giving an overall 2-year prevalence of 87 per 100,000 live births. The median age of the children affected was 1 year (range:3 months to 12 years old) and 42 (56%) were diagnosed in 2015. Of the 75 case-patients, 37 (49.3%) were congenital hydrocephalus, and 5 (6.7%) were post-meningitis acquired hydrocephalus. Forty (53.3%) of the case-patients from QMMH had no record of the referring district hospital. Of the case-patient with data on referring district, 15 (20%) were from Maseru district and 5 (5%) were referred from Mohale's Hoek district (Table 1).

Socio-demographic characteristics of hydrocephalus cases identified at MH district

Eleven case-patients with paediatric hydrocephalus were identified in MH district during the study period, giving an overall 4-years prevalence of 211 per 100,000 live births and case fatality of 4/11 (36.4%). The median age was 3 weeks (range: 1 week - 12 months) at the time of diagnosis, and five of the 11 case-patients were diagnosed in 2015 representing the highest number diagnosed in a single year. Of the 11 case-patients identified, 2 (18.2%) were congenital hydrocephalus, 2 (18.2%) were hydrocephalus acquired post meningitis and 7 (63.6%) had hydrocephalus of unspecified origin. However, among unspecified hydrocephalus case-patients, 5 (45.5%) were diagnosed within the first month after birth, suggesting probable congenital causes. (Table 2).

Characteristics of the mothers of hydrocephalus patients in MH district

Of the 11 case-patients located in MH district, nine were under the care of their biological mothers at the time of the investigation and two were under the care of a caregiver. The median age of the mothers of the 11 case-patients was 27 years (range: 17-38). Six (6/11) of the mothers had attained at least secondary level education; six (6/11) were married; and nine (9/11) had at least one more child in addition to the case-patient. Six (6/11) of the mothers were known to be HIV positive at the time of giving birth to the case-patient, however, all the HIV exposed children tested negative for HIV. Nine (9/11) of the mothers were not employed and none had access to government social grants to support the care of the affected child (Table 3).

Prenatal and perinatal history of the cases-patient in MH district

Two of the 11 case-patients were delivered at home, and their mothers had not accessed any formal antenatal health services during the pregnancy. Among the nine cases born in health facilities, four (4) were delivered through an emergency caesarean section, following a diagnosis of either cephalopelvic disproportion or prolonged labour. None of the 11 mothers had obstetric ultrasonography done during the course of pregnancy. One of the mothers reported that she visited a traditional healer during the course of the index pregnancy, and another 7 (53.8%) reported visiting a traditional healer at least once after giving birth (Table 3).

Medical management of the paediatric hydrocephalus

Figure 1 summarizes the referral process of the hydrocephalus patients from MH district to QMMH and then to the referral hospital in neighbouring South Africa for surgery. Ten out of the 11 hydrocephalus cases that we identified in MH district had been referred to QMMH for further evaluation and management at some point, and all the 10 cases were referred onwards to a hospital in South Africa for further neurosurgical evaluation and possible surgery.

Ventriculoperitoneal shunt (VP) insertions were performed in five patients, with an average delay of 107 days from the date of hydrocephalus diagnosis to the date of first surgery. The delays were largely attributable to delays experienced by the caregivers to obtain the necessary travel documents to take patient to South Africa and delays in securing a clinic consultation appointment date with the neurosurgeons in South Africa. Some caregivers also highlighted that they did not have transport funds to take the child to QMMH after referral from MH district.

All the five children who had VP shunts successfully inserted in South Africa had developed some post-surgery complications that necessitated the removal of the shunts. The complications included the following: blocked shunt (4) and infection (1). Of the five cases who had surgery only one (1) patient had managed to attend the recommended post-surgery follow up visits at QMMH after the shunt was inserted. The reasons given by the parents or care-givers for not attending follow-up visits largely centred on the lack of money for transport to travel from MH to QMMH.

Discussion

Our study attempted to estimate the prevalence of hydrocephalus in Lesotho and found a national prevalence of 87 per 100,000 live births and 211 per

100,000 live birth in MH district. Our findings suggest that the rate of hydrocephalus cases in Lesotho was lower than rates reported in Uganda (350 – 550/100,000 births), but was higher than reported in Mozambique (18/100,000 births) [6,9]. However, the small number of cases at MH district prevent firm conclusions regarding whether rates observed were above expected and no epidemiological links or casual associations were observed. Furthermore, ascertained cases are probably not a complete reflection of hydrocephalus patients in Lesotho, considering that QMMH is not centrally located, and therefore, it is probable that some cases referred from districts never made it. It is also plausible that some cases especially children that were born with congenital hydrocephalus were never referred from the districts to QMMH, particularly those that occurred in areas where the communities still practice the tradition of 'keeping children with disabilities hidden' because of the associated stigma or for cultural reasons [3,14].

We found poor antenatal care (ANC) attendance, and none of the mothers had access to ultrasound scan during their pregnancy. ANC is a public health interventions aimed at preventing maternal and perinatal morbidity and mortality, through detection and diagnosis of pregnancy-related complications [15,16]. World Health Organisation (WHO) recommends a minimum of four visits of ANC; and B-vitamin "folic acid" given during pregnancy help in brain development of the child and consequently reduces the risk of congenital disabilities including hydrocephalus [16,17]. The use of traditional healers and traditional medicine during and after pregnancy was common among this community, this may have resulted in delayed seeking medical care and subsequently the diagnosis of hydrocephalus.

Findings from the investigation of the cases that we identified in MH District suggest that surgery is largely delayed for most cases (an average delay of about 3 months), mainly because of delays in obtaining travel documents, in securing bookings at neighbouring South Africa hospital and greater distance to South Africa. Experiences from developed countries have shown that early treatment of hydrocephalus minimizes the damage to the brain tissue, and increases the likelihood of the child reaching a normal lifespan with fewer limitations [2,18,19]. Thus, delaying the surgery significantly lowers the probability of survival, and increases the likelihood of the child having intellectual, physical, and neurological sequelae [18]. The high case fatality rate we observed at MH District was possibly a result of the delays in performing the surgical procedures or complications associated with shunting.

We found high rates of complications after surgery for shunt insertion, among the five cases that had shunt successfully inserted. Previous studies have shown that the risk of shunt failure is highest within the first year after shunt insertion and that up to 30% of shunts may require replacement within the first year [11,20]. A study that was done in Harare (Zimbabwe) reported that 89% of the patients developed complications after shunt insertion [12]. The most common complications include shunt occlusion, over-drainage of CSF, subdural hematoma and shunt infection [20,21]; and these need to be detected early to minimize the damage. However, findings from our investigation show that the monitoring of patients after shunt insertion and the early treatment of shunt complications is made difficult by the complicated logistics of referring patients between health facilities.

Our study encountered several limitations. First, the data lacked some critical data elements that would have helped us to have a better picture of the burden of hydrocephalus in Lesotho (such as district name, specific diagnosis, type of hydrocephalus) and characteristics of mothers of children with hydrocephalus in QMMH. We were unable to obtain permission to review medical records of children with hydrocephalus transferred to South Africa for surgery and could not access data on hydrocephalus for the years before 2015. As a result, our investigation could not decisively conclude whether the observed numbers of hydrocephalus cases exceeded what would be considered normal for the population of Lesotho. In addition, we could not ascertain trends accurately in the numbers of cases of hydrocephalus or prevalence rates over a longer period, and state with absolute certainty if there was a real increase in the occurrence of hydrocephalus in Lesotho over the years. Despite these limitations, our findings provide a reasonable picture of the burden of paediatric hydrocephalus in Lesotho and the existing gaps in the healthcare management of the patients with hydrocephalus in MH district.

Conclusion

Our study provides an insight into the burden of hydrocephalus in Lesotho and MH district; and delays in referral for VP shunt surgery and suboptimal post-surgery follow-up of children with hydrocephalus. We recommended that the MoH in Lesotho implement a community-based national surveillance system for congenital abnormalities, embark on health campaigns to increase community awareness about hydrocephalus and promote early reporting. The Government of Lesotho, particularly the Ministry of Foreign Affairs should facilitate travel documentation and strengthen inter-countries referral system to reduce delays among patients referred to South Africa requiring emergency medical care. In addition, the MoH should consider strengthening the capacity for neurosurgical procedures and post-surgical rehabilitation care to be performed at QMMH to improve management outcomes for children with hydrocephalus.

Competing interests

The authors declare that they have no conflicts of interest.

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Authors´ contributions

RM and LK were involved in the conception, design of the study, data collection, data analysis and interpretation. LM, TM, ML and OA contributed to data interpretation and revision of the manuscript for intellectual content. All authors critically revised the manuscript and approved the final version.

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Tables and figures

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Figure 1: Flow diagram summarising the referral process of the patients from Mohale's Hoek District to neighbouring South Africa for surgery, 2013-2016

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Table 1: Characteristics of paediatrics hydrocephalus patients identified at Queen Mamohato Memorial Hospital, 2015 - 2016		
Characteristics	**Frequency** n=75	**(%)**
Gender		
Female	40	53.3
Male	35	46.7
Year of diagnosis		
2015	42	56.0
2016	33	44.0
Type of hydrocephalus		
Congenital	37	49.3
Acquired post-meningitis	5	6.7
Unspecified	33	44.0
Age during diagnosis (years)		
< 28 days	14	17.3
1 months – 1 year	34	45.3
>1 year	28	37.4
District		
Maseru	15	20.0
Leribe	6	6.7
Mohale's Hoek	5	6.7
Berea	4	5.3
Other	5	6.7

Table 2: Characteristics of paediatrics hydrocephalus case-patients identified at Mohale's Hoek district, 2013 – 2016		
Characteristics	**Frequency** n=11	**(%)**
Gender		
Female	9	81.8
Male	2	18.2
Type of hydrocephalus		
Congenital	2	18.2
Acquired post-meningitis	2	18.2
Unspecified	7	63.6
Age during diagnosis (years)		
< 28 days	5	45.5
months – 1 year	5	45.5
>1 year	1	9.1
Year of diagnosis		
2013	2	18.2
2014	2	18.2
2015	5	45.5
2016	2	18.2

Table 3: Characteristics of mothers of hydrocephalus patients in Mohale's Hoek District, Lesotho, 2013 – 2016		
Characteristics	**Frequency n=11**	**(%)**
Marital status		
Single	5	45.5
Married	6	54.5
Highest educational level		
Primary	5	45.5
Secondary	6	54.5
Number of children		
1	2	18.2
2+	9	81.8
HIV status		
Positive	6	45.5
Negative	5	54.5
Employment status		
Unemployed	9	81.8
Informal job	2	18.2
Receive social grant		
Yes	1	9.1
ANC attendance		
0	2	18.2
2	4	36.4
3	2	18.2
Unknown	3	27.3
Mode of delivery		
Normal Vaginal	7	63.6
C/S	4	36.4
Place of delivery		
Hospital/healthcare facility	9	81.8
Home	2	18.2
Visited traditional healer during or after delivery		
Yes	7	63.6
ANC: antenatal care, C/S: caesarean section, HIV: human immunodeficiency virus		

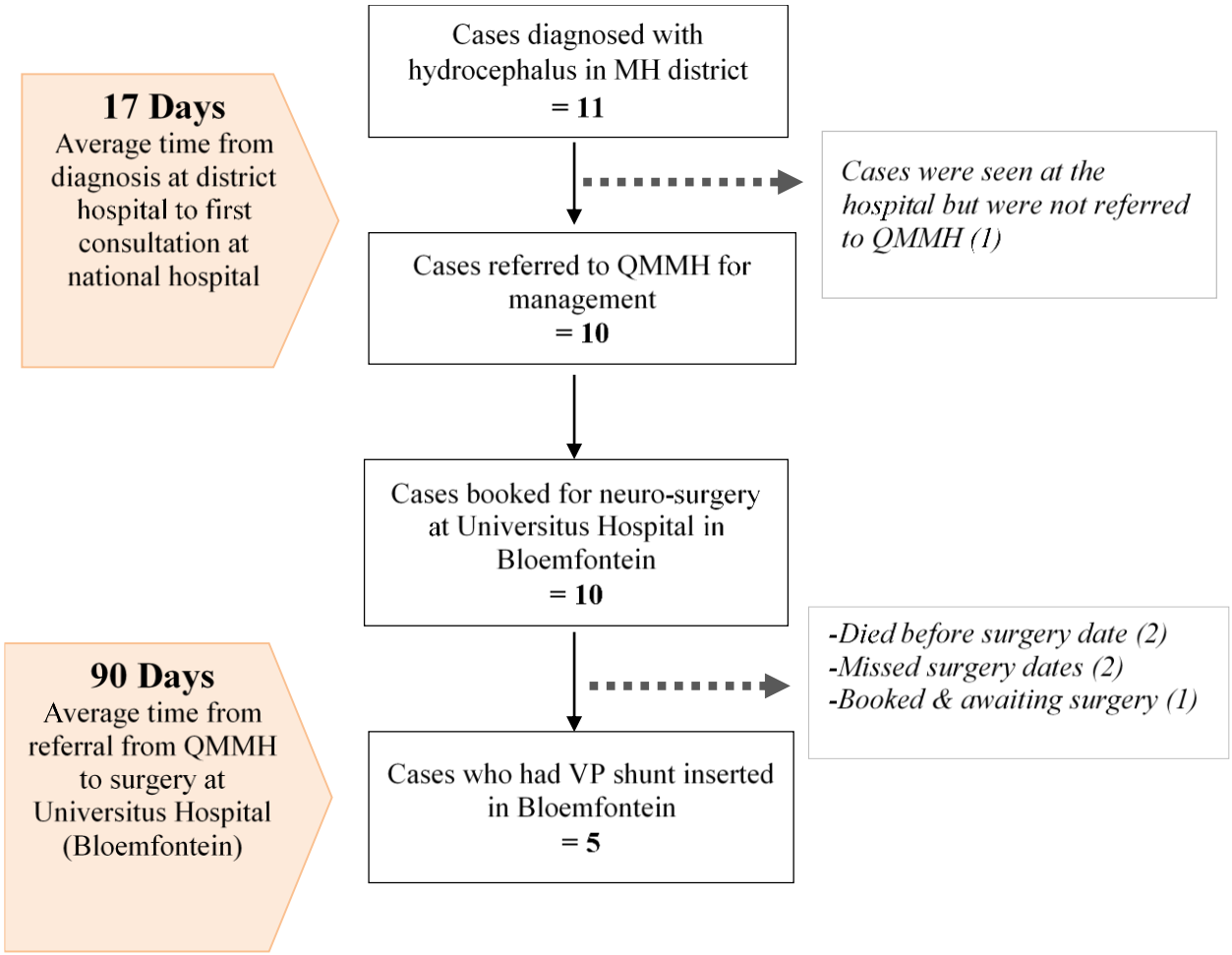

Figure 1: Flow diagram summarising the referral process of the patients from Mohale's Hoek District to neighbouring South Africa for surgery, 2013-2016