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Encephaloceles In Kenya: A Retrospective Analysis Of Risk Factors, Caregiver Burden, And Healthcare Challenges

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ABSTRACT

Introduction: Encephaloceles are rare congenital defects characterised by a cranial defect with herniated content resulting from the failure of skull bone fusion or rostral neuropore closure. The specific aetiology of the condition is unknown but may result from maternal micronutrient deficiency, infections, genetic predisposition, environmental factors, and drug use. **Methods**: A case series study was carried out at Kenyatta National Hospital to identify the risk factors for encephalocele among patients treated there between 2015 and 2021. Telephone interviews were also conducted to determine the presence of emotional and psychological distress among the patients' carers. The transcription and analysis of recordings were done. **Results**: A total of 47 patient files were included in the study, and 16 caregivers completed the telephone interviews. The most common type of encephalocele was occipital and was more common among males. Most patients were diagnosed at birth; 56% of mothers attended four or more ANC visits; only 25% completed a folic acid regimen; 6% of caregivers had extreme depression; and 13% had severe depression. **Conclusion**: Encephaloceles impose considerable emotional, psychological, and financial burdens on caregivers, hence indicating a substantial need for psychological support.

Keywords: Encephalocele, neural tube defects, neurosurgery, congenital defects, IFAS, antenatal care.

INTRODUCTION

Encephaloceles are neural tube defects (NTDs) characterised by herniation of the brain and meninges through a defect in the skull (1). Encephaloceles are categorized according to the location of the defect on the skull relative to the coronal suture, they include frontal/ anterior encephaloceles and

occipital basal encephaloceles (1, 2). Studies show that the prevalence of encephalocele varies across time; in low- and middle-income countries, it is estimated to be 2.1 per 10,000 live births; in Africa, it ranges between 0.8 and 4.0 per 10,000 live births (3). The prevalence of this condition in Kenya is still unclear.

The exact cause of encephaloceles is unknown; however, genetic, environmental, and nutritional factors have been identified. The most significant risk factor is folate deficiency; other factors include maternal infections such as toxoplasmosis, rubella, cytomegalovirus, herpes simplex, and others (syphilis, hepatitis B) or TORCH infections, nonsteroidal anti-inflammatory drugs (NSAIDs), anticonvulsants, maternal obesity, diabetes, and advanced age at conception (4–6).

This study aims to identify the risk factors linked to encephalocele, the factors affecting access to care for these patients, and to shed light on the psychological effects of caring for patients afflicted by the disease.

METHODS

Hospital records for paediatric patients managed at Kenyatta National Teaching and Referral Hospital (KNH) who were managed for encephalocele from 2015 to 2021 were collected from the records department from June 2022 to May 2023. KNH is the largest public hospital in the country and serves as a neurosurgical referral facility.

The KNH and University of Nairobi Ethics and Research Committee (KNH-UON ERC) provided ethical approval for this study (P981/12/2021). Informed consent was taken from participants over the phone before the administration of the questionnaire; the consent was adapted to the study per the ERC-approved format and was provided in English and Swahili.

Patients who presented with encephalocele between January 2015 and December 2021 were included in the study. The convenience sampling method was utilised, and we selected patient files that included a diagnosis of encephalocele, patient characteristics, and contact details for the next of kin or carers.

Caregivers interviewed included mothers, fathers, relatives or guardians who stepped in for the parents and had adequate knowledge regarding the medical history of the child in the duration they presented to the hospital.

Cochrane's formula for finite populations was used to calculate the sample size for the study; we aimed to identify 384 patient files from the records department. We collected data in two phases: first, patient biodata such as year of birth, gender, county of origin, diagnosis, and telephone contacts of next of kin was collected from patient files; then, we interviewed next of kin via telephone using a standardised questionnaire containing open and close-ended questions to obtain history and management details not captured in files. Carers were also assessed for depression using the Beck Depression Inventory (BDI) as shown in Table 1; the questionnaires were provided in English and Swahili.

Statistical analysis: Interviews were recorded, transcribed, and analysed; the research team performed statistical analysis with SPSS version 23, Microsoft Excel. The independent variable for this study included the diagnosis of encephalocele. Dependent variables include type of encephalocele, demographic characteristics, maternal health history, diagnosis and management and BDI score. Respondent and participant ages were treated as continuous variables, the mean and standard deviations were calculated for maternal age, sex, counties of origin, and BDI score were analysed.

Table 1: *The Beck's depression index used in the study.*

Total Score	Levels of depression
1-10	Normal
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
Over 40	Extreme depression

RESULTS

Sociodemographics

Fifty patient files were selected from the records department at the hospital; 47 met the inclusion criteria (**Figure 1).** Of these patients, 17 (36%) and 30 (64%) were female; the most common encephalocele identified was occipital (53%), followed by frontal (28%). In 9 (19%) patients, the type of encephalocele was not specified. There were more males with occipital encephalocele (n=17, 36%) than females (n=8, 17%), similarly, more males were diagnosed with frontal encephalocele (n=9, 19%) (**Table 2**).

County of residence

Twenty-seven patients (57%) presented to KNH in the first week of life, 9 had presented by 2 weeks, 3 at 4 weeks, and 7 presented after eight weeks of life. Patients travelled from 14 counties to seek care at KNH. 21 (45%) patients were from Nairobi County, followed by Kiambu (6), Makueni (4), and Garissa (3), as shown in Figure 2 and Table 3.

Characteristics of the responders

In phase 2, 16 respondents completed the telephone interview. The respondents were family members, the majority of whom were mothers, as shown in Table 4. Most respondents were from Nairobi (n=6, 37.50%); others were from Kiambu (2), Nyeri (2), Meru (1), Siaya (1), Kisumu (1), Kisii (1), Kitui (1), and Machakos (1). Half (8) of the interviewed respondents reported completing primary education, 6% had completed secondary education, and 19% completed tertiary education. One participant did not undergo formal education, while the educational backgrounds of the three participants were unknown. Fifty percent of the patients were deceased at the time of the interview, with 44% surviving; of note, one of the respondents reported a loss of contact with their child. The oldest living patient is ten years old, with the youngest being two years old. The age range of the deceased was five weeks to 2 years

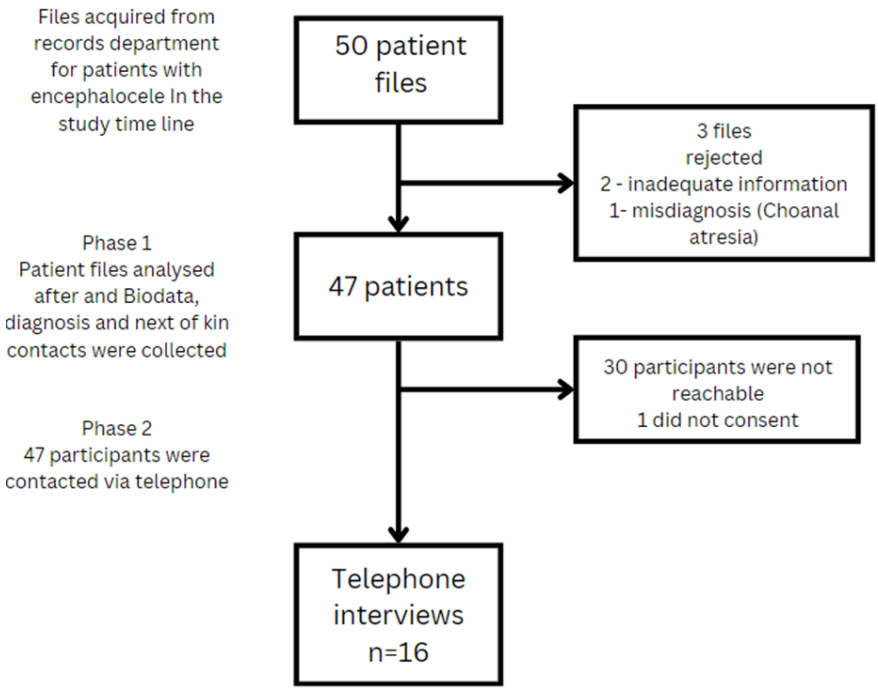

***Figure 1**: A summary of the data collection process. 50 patient files were retrieved; of these, 3 files were rejected due to incomplete data or inaccurate diagnosis. In phase 2 of the study, we contacted all the 47 contacts listed on the files, and 16 carers completed the questionnaire.*

***Table 2:** The sexes and distribution of encephalocele cases*

	Number (N=47)	Percent
Sex		
Male	30	64
Female	17	36
Encephalocele type		
Frontal	13	28
Occipital	25	53
Encephalocele	9	19
Encephalocele Distribution among Sexes		
Male	30	64
Frontal	9	19
Occipital	17	36
Encephalocele	4	9
Female	17	36
Frontal	4	9
Occipital	8	17
Encephalocele	5	11

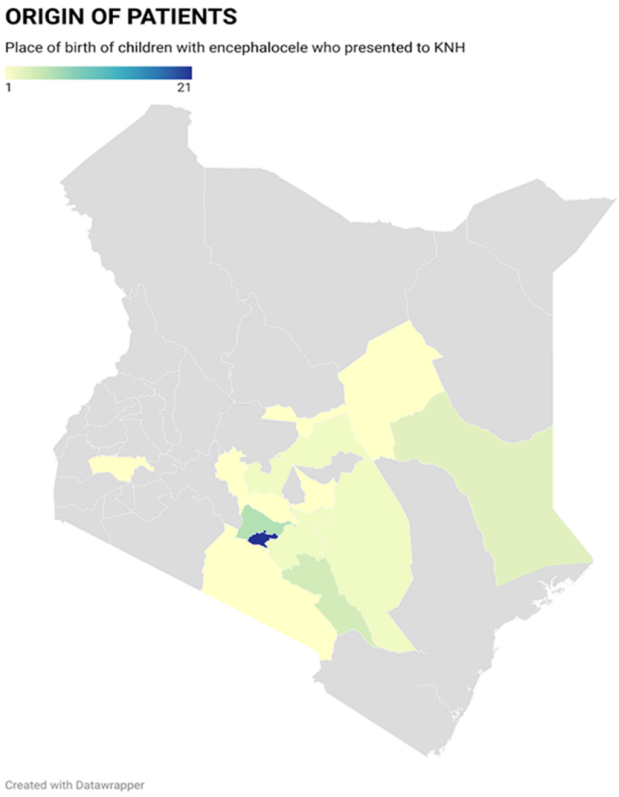

Figure 2: *This map illustrates the counties of residence of children with encephalocele who were referred to KNH. The color intensity corresponds to the number of cases from each county.*

Table 3: *County of origin of patients presenting to Kenyatta National Hospital 2015-2021*

Residence	Number of patients	%
Nairobi	21	45
Kisumu	1	2
Nyeri	2	4
Garissa	3	6
Kajiado	1	2
Embu	1	2
Machakos	2	4
Meru	2	4
Nyandarua	1	2
Kiambu	6	13
Isiolo	1	2
Kitui	1	2
Murang'a	1	2
Makueni	4	9

Table 4: *Characteristics of respondents (n=16) and their children*

Characteristics		Number (N=16)
Respondents	Mother	7
	Father	5
	Both parents	1
	Relative/ Guardian	3
	Total	16
Education of Respondent		
	No education	1
	Primary School	8
	Secondary school	1
	Tertiary	3
	NA	3
	Total	16
Sex of the children		
	Male	7
	Female	9
Status of the child at the time of the interview		
	Living	7
	Deceased	8
	NA	1
	Total	16

Maternal factors

The mean maternal age was 31.56 years (range 22-38 years). 4 respondents reported that the mothers did not have sufficient food during the pregnancy as a result of financial constraints. None of the carers reported any physical injuries to the mothers during their prenatal period. Three respondents reported a history of perigestational anaemia among the mothers. Other reported maternal issues included gestational hypertension (1), seizure disorder (1), and marijuana use in 2 cases. None reported alcohol.

Antenatal clinic visits (ANC)

Nine (56%) mothers visited the ANC more than 4 times; one respondent had 3 visits. 2 (13%) visited twice; one mother only visited once. 3 (19%) respondents were unable to report on the ANC visits. Half of the respondents reported that the mothers had taken folate during pregnancy. Of these, only half (n=4, 25% of total respondents) took the recommended dose to completion. Thirty-one percent said that the mothers had not taken folate. Fathers and other carers could not give this information.

When asked whether the respondents understood the importance of folate supplementation in pregnancy, 44% did not understand, 4 (25%) answered in the affirmative, and 5 (31%) did not respond.

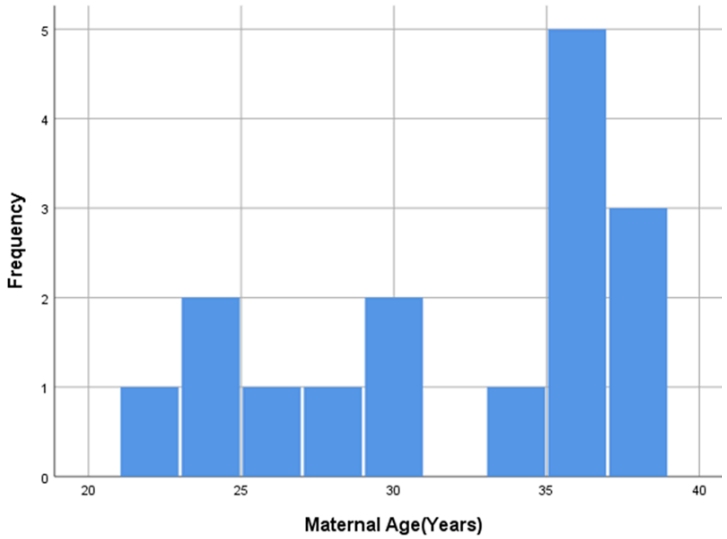

Figure 3: *The distribution of maternal ages at the time of birth as reported by 16 interviewed correspondents (mean = 31.56, Std.Dev = 5.633).*

Diagnosis and Management

All the diagnoses of encephalocele were postnatal, with 9 diagnosed at KNH; the rest were referred from peripheral healthcare centres. The mean distance traversed by patients was 26.08 km, with an average travel range of 1 km to 124 kilometres. At the point of diagnosis, 56% reported they did not receive a clear explanation from the healthcare providers of the cause, nature, and status of their child's condition; however, 38% reported receiving an explanation and understanding their child's diagnosis.

Twenty-four (51%) of the 47 patients had identifiable co-morbidities recorded in the files; 12 (25.5%) presented with microcephaly, 6 (12.8%) presented with hydrocephaly, 3 (6.4%) presented with cleft lip and palate, and 3 (6.4%) patients were diagnosed with multiple defects, including spina bifida, craniofacial dysmorphism, and genitourinary defect. Additionally, 7 of the 16 interviewed carers reported delayed growth and developmental milestones in the patients.

Eleven participants reported a delay in receiving care for their infants at KNH; the respondents cited many reasons for the delay, including financial constraints, lack of bed space, and absence of healthcare workers and neurosurgeons; 2 participants did not respond to this question.

Eleven respondents found the cost of care very high, 4 did not report any such difficulties, and one respondent was unaware of the costs as they had lost contact with the patient after diagnosis. The carers employed multiple methods to pay for the healthcare for the children; 9 reported that the National Health Insurance Fund (NHIF) subsidised the cost, 4 respondents had to meet the total cost of medical care themselves, one carer used private insurance, and one respondent was unable to respond. Other sources of funds included bank loans and money from the sale of property.

Table 5: *Payment methods utilised by caregivers, n=16*

Method of payment	Respondents	Number of respondents (%)
NHIF	9	56
Private Insurance	1	6
Out of Pocket	4	25
NHIF Plus Private insurance	1	6
No response	1	6

Mental health and social factors

The 16 respondents were assessed using Beck's depression inventory (BDI); one respondent scored more than 40 points on the BDI, which showed extreme depression, while 2 showed severe depression (31-40 points). Over half (n=9) of the interviewed caregivers acknowledged experiencing stigma due to their child's condition, and two carers did not respond. One participant expressed experiencing feelings of being stigmatised by healthcare professionals at the medical facility; this mother reported that she was blamed for her child's condition as she had not taken her supplements. Six respondents said they had received support from their community and did not perceive any stigma. This question was left unanswered by one respondent.

All interviewed participants reported no medical, financial, or psychological support from governmental or nongovernmental organisations (NGOs). Only one participant indicated awareness of an NGO dedicated to caring for children with disabilities through their physiotherapist. The participants mentioned receiving assistance in terms of fundraising and social support from community or religious groups.

Table 6: *Caregiver score according to Becks depression inventory*

Beck's scale	Number of patients (n)	Participants (n=16)
Normal	5	31%
Mild Mood disturbance	4	25%
Borderline clinical depression	3	19%
Moderate depression	1	6%
Severe depression	2	13%
Extreme depression	1	6%

DISCUSSION

This study is the first of its kind to be conducted in the country with the purpose of identifying the risk factors, factors affecting the access to care for children with encephaloceles and how this condition affects the mental health of caregivers

The majority of encephaloceles in our sample were located in the occipital region. Research suggests that around 70-80% of encephaloceles are located in the occipital region, although this proportion differs across various geographical regions. In North America and Europe, occipital encephaloceles comprise 85%, whereas research in India reveals that they account for 60%. In contrast, other studies indicate that in Africa, Asia, and Europe, anterior encephaloceles predominate, occurring in 1 in 35,000 to 6,000 live births (7).

The distribution of encephalocele concerning sex is not sufficiently documented; some studies indicate no correlation, while others suggest a higher prevalence in females. A Nigerian study identified a female predominance with a ratio of 1:0.7 (F:M), contrasting with our findings, where the majority of subjects were male (64%). Additionally, occipital encephaloceles were more prevalent among males, with 17 out of 25 cases; however, it is estimated that 70% of occipital encephaloceles occur in females (1, 6).

Risk factors

The uptake and compliance with folic acid administration among carers in our study group were minimal, since most did not comprehend the significance of this supplement. This aligns with studies in low- and middle-income countries such as Vietnam, Ethiopia, and Zimbabwe. A study conducted in Kenya on iron and folic acid supplementation (IFAS) revealed that 53% of mothers did not receive an explanation on the significance of the supplement during their ANC visits, and 26% of mothers lacked understanding of its benefits for the foetus (8). Awareness of the significance of folic acid supplementation is limited; yet, it is crucial in preventing neural tube defects (NTDs), with studies indicating a reduction in prevalence among neonates by as much as 58% (9).

Approximately 30 percent of women worldwide utilise folic acid supplementation prior to conception (10). The prevalence of folate deficiency in Kenya is currently unknown (9). IFAS is typically administered to women visiting the initial ANC clinic. The administration of this supplement at this stage has been shown to be ineffective in preventing neural tube defects (NTDs), given that the anterior neuropore closes on the 25th day of embryogenesis (7). Research indicates that most women experiencing unintended pregnancies conduct their pregnancy tests at 6 weeks, which is 2 weeks later than those with planned pregnancies and considerably later than the period during which folate supplementation is beneficial (11). The Kenyan government has aimed to mitigate folate deficiency by fortifying wheat with vitamins and iron; nonetheless, access to these fortified foods is limited by socioeconomic factors (9).

Significant improvements have been made in Kenya in relation to ANC and Folate supplementation, according to the Kenya Demographic and health survey (KDHS) In 2022, 98% of women reported receiving antenatal care in their most recent pregnancy, 66% had four or more ANC visits, and 9 in 10 women took iron-containing supplements (12). Although these statistics are significantly better than the results of our study, we believe that there is still a lack of knowledge and awareness among women of the importance of folate supplementation and adequate ANC visits.

The oldest mother in our sample was 38 years old. Advanced maternal age is a risk factor for numerous congenital anomalies, including NTDs; a 2013 systematic review and meta-analysis reported that women over 35 years old were 2.5 times more likely to give birth to a child with encephalocele than women under 20 (5).

Half of the carers in this study received primary education; studies show that fewer years of formal education limit earning potential and awareness about folate supplementation (13). A Kenyan study found that an individual's earnings increase by up to 10% with one additional year of schooling, and university graduates earn an average of three times more than their primary school counterparts (14). Individuals with a higher level of education are more likely to be familiar with health-seeking behaviour and have better access to healthcare, influencing patient outcomes.

Diagnosis and Management

Poor ANC clinic attendance can be associated with late diagnosis, as first-trimester and second-trimester ultrasound can be used to identify congenital anomalies. Usually, prenatal ultrasounds performed between the 9th and 11th weeks of pregnancy show a fluid sac; by 13 weeks, a meningocele or encephalocele can be identified (7). A radiological study showed that traditional 2D ultrasounds detect 80% of encephaloceles in the first and second trimesters (15). The The efficacy of ultrasonography in diagnosing cranial defects is limited by factors such as the varying degree of brain herniation, the mother's body orientation, the position of the foetus, and the surrounding amniotic fluid (16, 17). There is a need to improve the education of women of reproductive age on the importance of receiving obstetric ultrasound scans as recommended; furthermore, reviewing imaging and diagnostic practices in the ANC service and improving the technologies, skills, or awareness among healthcare workers would improve the accuracy of this modality in detecting encephalocele. Lack of skilled ANC personnel or inadequate ANC visits are associated with increased neonatal mortality in Kenya (13)

The most optimal time for surgery for occipital encephalocele is between birth and four months, while that of anterior or basal may be delayed up to 2-3 years (7). Surgery may be delayed for multiple reasons, including the location of the lesion, size, and concomitant conditions (15). Financial factors are a significant cause of delay in seeking surgical care in LMICs; high surgical fees, prolonged hospital stays, and costs of medication and supplies are direct costs of hospitals, while indirect costs include the loss of time and wages among patients and carers. Previous studies in Kenya have found that 14.6% of hospitals required cash deposits or guarantees of payment before admitting surgical patients, 22.3% of patients owed more than $133 to hospitals. In comparison, only 19.7% of these patients were in a position to pay, and 58.7% required financial assistance from their relatives and friends (18). Similarly, a Nigerian study identified exorbitant costs, geographical inaccessibility, and limited knowledge as significant barriers to neurosurgical care (19). The lack of accessible specialist surgical care in most counties in Kenya is a significant cause of delay in Kenya. There are currently 39 licensed neurosurgeons in Kenya, resulting in a ratio of one surgeon per 1.2 million Kenyans compared to 1 per 65,000 individuals in the United States (16,20).

The scarcity of qualified labour may also be worsened by the absence of medical officers and nurses due to recurrent strikes and poor patient and health worker ratios at local hospitals, as such patients and carers end up travelling many kilometres from across the country at significant financial and time costs to access referral facilities like KNH. In addition to the cost of surgery and transport for patients, the cost of caring for children with encephalocele is complicated by comorbidities that require continuous medical or surgical care, for instance, treatment of concurrent conditions such as convulsions,

hydrocephalus, and infections, follow-up consultations, and multiple admissions; some of these medications and equipment, such as shunts for hydrocephalus, are available at private pharmacies where they are costly and cannot be paid for by the NHIF.

Poor communication between healthcare staff and patients or carers is a significant barrier to effective referrals between healthcare facilities; this often adds to a lack of patient understanding and awareness about the conditions. In some cases, carers reported that their children were misdiagnosed and treated for other conditions; this predisposed the patients to the adverse outcomes of delayed care for carers like hydrocephalus. Other reports of mismanagement of encephalocele exist in research, for instance, the management of myelomeningocele at a local hospital with daily dressing changes; this is similar to a response by one of the carers at KNH, who reported that their child was treated for growth for some time before being referred to KNH; misdiagnosis is a significant cause of delayed presentation in NTDs (19).

Prognosis

Occipital encephaloceles are known to carry a poorer prognosis than anterior encephaloceles due to the higher incidence of hydrocephalus and seizure disorders; other factors increasing mortality in this population include low birth weight, multiple intracranial defects, and black ethnicity. Surgical care for the condition may also cause significant complications such as CSF leaks, meningitis, seizures, and hydrocephalus (7). While these reasons might explain the 50% mortality reported in this study, the prognosis of encephalocele depends on many factors, such as location, size, the size of the affected brain, other congenital anomalies, the presence of dural sinuses in the sac, and hydrocephalus. This echoes the 55% survival rate for occipital encephaloceles stated by the CDC (21); other studies predict a mortality rate of between 4-30%, with the majority of deaths (76%) occurring on the first day of life (7).

Studies show that 48% of children with encephalocele have normal growth and development; this is close to the number in this study (56%) (7); however, nearly half of the patients with occipital encephalocele cannot live independently in society. While we did not find any reports of patients requiring specialised education or care, many patients with this condition lack typical developmental milestones and have neurological deficits like visual impairment, seizures, and mental and growth retardation (7). These complications add to the treatment cost due to occupational and speech therapy and prolonged carer dependence.

Mental Health and Stigma

The psychological well-being of carers is greatly affected by encephalocele. The various sources of distress include inadequate finances, concerns about the well-being of their child, frequent episodes of illness and hospitalisations, societal prejudice, ignorance of the condition, and infant mortality. A considerable number of carers reported emotional discomfort following the birth of their child. Individuals exhibited personal accountability for their child's illness, with comparisons made to their other children and reflections on their own perceived inadequacies. Carers reported perceiving their child's health as a form of retribution for imagined offences done by either themselves or the community; for example, accusations of infidelity were brought forward. The participants' psychological state was significantly affected by their restricted understanding and knowledge of the disease, frequently enduring for a lengthy duration, even following the child's death. It would be instrumental for healthcare workers to ensure understanding of the condition amongst caregivers to resolve their confusion and uncertainty concerning the disease and how to think about it and make decisions.

Families of children with congenital anomalies frequently prefer to keep their children's diagnoses hidden from the community for fear of facing stigma; mothers of these children

often have a higher level of anxiety, which is often worse after birth compared to the prenatal period (19). We discovered that encephalocele stigma emanated from the general community and, in some cases, healthcare providers; Ignorance regarding the causes of encephalocele allows such beliefs to prevail

Carers exhibited symptoms of mental distress. Weight loss, reduced appetite, a pervasive feeling of illness, sleep disturbances, heightened irritability, diminished motivation, increased frequency of crying, worsened body image, loss of intimacy with partners, and feelings of isolation were present. Inadequate communication from healthcare professionals was a noteworthy contributor to distress. Several carers expressed a lack of comprehension regarding their child's condition despite receiving a diagnosis and ongoing management at a medical facility. Some reported instances of healthcare workers displaying rudeness and making accusatory remarks. One mother reported stigmatisation by nurses for not adhering to folic acid supplementation.

Carers used a variety of coping techniques. Religious faith and trust in God strengthened their belief in their abilities to overcome their problems. Certain people were motivated by an inherent commitment and accountability to their children. Community and family support was critical. Both allowed them to participate in discussions and pray with other parents in similar situations. Some people used harmful coping mechanisms such as increased alcohol consumption and self-isolation.

Nongovernmental organisations

The International Federation for Spina Bifida and Hydrocephalus (IFSBH), the Spina-Bifida Hydrocephalus Association of Kenya (SHAK), and Child Health Global are a handful of groups that provide care and support for patients and carers with NTDs in Kenya; however, the majority of these organisations focus on spina bifida as it is more common; therefore, carers for children with encephalocele are unable to utilise services from these organisations. Additionally, there is a lack of awareness of them among the target population. This might explain the lack of contact with the study population. A transparent and functional relationship between the government and NGOs in providing care for children with encephalocele can provide much-needed support to patients and providers in low- and middle-income countries. Nongovernmental organisations (NGOs) provide expertise in research and development, illness screening and prevention, and outcome monitoring (19).

Study limitations

The study was retrospective and involved a rare congenital defect; the sample size of this study was limited, and this limits the generalisability of the findings of this study. This can be mitigated by conducting a prospective cohort study on patients and carers to improve the understanding of the topic.

The interviews in this study were conducted via the telephone; this created significant challenges due to the length, complexity, and invasiveness of specific questions, particularly those about mental health. Face-to-face interviews conducted at different points during the management process would improve the findings of this study.

The facility's paper-based patient record system lost files and incomplete patient information. However, a digital system is currently being developed. The study only considered one level 6 facility, therefore limiting the number of participants participating. This study utilised convenience sampling; this could explain the over-representation of males in the sample.

We were not able to adequately assess the socioeconomic status of the families or the nutritional status of the mothers during and

before pregnancy beyond the responses to the interviews. A more in-depth look at these factors would significantly improve our understanding of their relationship with encephalocele.

Recommendations

None of the participants received counselling or psychological review during the management inpatient or follow-up. However, religious support and community- and family-based counselling were prevalent. Therefore, we recommend more mental health support from healthcare services to meet the deficit that exists.

CONCLUSION

Encephalocele is still a prevalent NTD in Kenya despite the government's efforts to improve the antenatal care program and promote folic acid supplementation and fortification. There remains a need to educate mothers and women of reproductive age about the significance of nutrition and folate in the development of the foetus and the significance of ANC clinics in detecting, monitoring, and caring for pregnant women. The psychological well-being of carers is greatly affected by encephalocele. Inadequate communication from healthcare professionals was a noteworthy contributor to distress. More mental health support from healthcare services is required to meet the deficit that exists.

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