

EXPLORING THE SUPPORT PROVIDED TO MOTHERS WHOSE NEONATES ARE DIAGNOSED WITH GASTROSCHISIS IN KENYATTA NATIONAL HOSPITAL, KENYA

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ABSTRACT

Background: Gastroschisis is a rare congenital condition that occurs while a fetus is in the early stages of development which results in the abdominal wall having a protrusion of abdominal contents – large and small intestines and the stomach. Delivery of a neonate with chronic illnesses like gastroschisis greatly affects caregivers and mothers because neonates who do not receive surgical care immediately after delivery end up losing their lives, while those who do survive require extensive medical and comprehensive care and additional hospitalization which many parents are unsure of how to provide or are not able to afford. To contribute to the existing body of knowledge on gastroschisis, a phenomenological approach was used to draw from the experiences of mothers admitted at KNH providing care for their neonates diagnosed with gastroschisis; to ascertain whether they receive adequate support from the hospital and other people out of the hospital that are close to them.

Broad Objective: To explore the support given to mothers whose neonates are diagnosed with gastroschisis in KNH.

Methodology: Phenomenological descriptive research design was adopted in this study. In-depth interviews with twenty-five (25) mothers were purposively sampled, interviews were audiotaped, and the data was later transcribed and inductively analyzed into themes and sub-themes.

Findings: The results indicated that the mothers were positive about their pregnancies and attended antenatal clinics, mental symptoms exhibited by these mothers due to the nature of the neonates and the kind of support they needed from

family and health care providers. Additionally, both positive and negative relationship was exhibited between the mothers and the healthcare providers. Moreover, as a result of fatigue due to caregiving for children diagnosed with gastroschisis mothers experienced support from spouses, family members, healthcare givers, and peers. The study concluded Prenatal Experiences of Mothers with neonates with gastroschisis were positive and the majority of them were happy that they were pregnant and were ready to follow doctors' guidelines throughout the period.

Postnatally, the mothers experienced various mental challenges due to inadequate support from their close family members and inadequate information concerning the condition before their children were born. They too were unprepared to deal with the stress and difficulties related to the neonates' condition. The majority of the mothers received support from family members and fellow mothers with similar experiences.

Recommendations: A more thorough prenatal screening is recommended to assist in the early detection of such congenital disorders, which can direct birth preparations for the mother and child. Healthcare providers should consider the mental health of mothers with neonates born with congenital anomalies rather than concentrating on the neonates alone. To assist in easing the mental and emotional strain placed on parents, hospital staff should provide professional counseling. They should also encourage peer counseling among mothers. Additionally, it is recommended that future researchers consider different methodological

approaches in the collection and analysis of data related to gastrointestinal complications such as gastroschisis.

Keywords: Neonates; Gastroschisis

INTRODUCTION

Globally, there has been a rise in the prevalence of children born with gastroschisis in the recent past. This rising trajectory has been a culmination of the three-decade steady rise in the level of prevalence of gastroschisis (Burjonrappa & Snyder, 2021). Worldwide, statistics also suggest that the prevalence of gastroschisis is approximately 1 to 5 for every 10,000 live births, a result of the threefold increase in the last 10 years (National Library of Medicine, 2022). In the United Kingdom, the condition affects approximately 300 babies every year (NPEU, 2022). In the United States, reports indicate that 1 in every 1,953 are born with gastroschisis (CDC, 2023). With the use of modern treatment, survival of gastroschisis exceeds 90% in high-income countries as compared to low-income and middle-income countries (Wesonga, Situma & Lakhoo, 2020). The survival rate of gastroschisis is dependent on associated malformations and can vary between 80% and 88% (Tauriainen, 2023). In high-income countries, the mortality rate associated with gastroschisis is approximately between 4% and 8% while middle-income countries can experience up to 84% mortality rate (Machaea *et al.*, 2023). From the published statistics in the global South, the mortality rate associated with gastroschisis in sub-Saharan African countries is between 75 and 100% while in Kenya alone it is between 33 and 100%. These increasing and worrying statistics therefore justify the need to conduct research aimed at providing highlights on the challenges experienced by the caregivers and required interventions in terms of providing support for them.

Gastroschisis, sometimes referred to as omphalocele, is a congenital anterior abdominal wall defect that is rarely associated with other abnormalities of the congenital. It can also be referred to as a congenital anomaly that has an abdominal wall defect leading to bowel evisceration (Elrouby & Maher, 2021; Negash & Temesgen, 2022). Additionally, complications of complex cases of gastroschisis are associated with the following medical conditions: intestinal atresia, perforation, necrotic segments (Mcnelis *et al.*, 2022). On the other hand, the reasons for the occurrence of the gastroschisis condition have been explored in prior research, and among the reasons that lead to neonates with gastroschisis condition are the mother's young age, alcohol, and tobacco abuse as well as genitourinary infections. Environmental factors can also lead to incidences of gastroschisis. Additionally, one of the core causes of the condition in the embryonic period is the rapture of the physiological hernia (Bhat, Moront & Bhandari, 2020; National Library of Medicine, 2022; CDC, 2023). Moreover, research in Ontario Canada suggests that mothers with babies with gastroschisis are more likely to be young, implying that young age can be a risk factor in the occurrence of gastroschisis (NIH, 2021). Some researchers have classified the complexity levels of gastroschisis, as both simple and complex depending on the presence or absence of bowel perforation, internal atresia stenosis, volvulus, or necrosis. Additionally, some nursing

researchers take note of the fact that outcomes and management of infants with complex gastroschisis especially those diagnosed with short bowel syndrome (SBS) has remained a huge challenge (Rentea, & Gupta, 2020; Bhat, Moront & Bhandari, 2020). Yet another approach that can be used in identifying gastroschisis is both postnatal and prenatal by the location of the defects most often to the right of the normally inserted umbilical cord (Bhat *et al.*, 2020).

Gastroschisis can be manifested through various complications such as herniation of the midgut bowel into the amniotic cavity through a para-umbilical full-thickness wall defect, that is most commonly to the right of the cord insertion (Aboughalia *et al.*, 2020). They can also be manifested by way of the presence of sepsis, volvulus, necrotizing enterocolitis, and perforation among others (Ferreira *et al.*, 2022; Lavinia & Debarge-Houfflin, 2024). Empirical studies indicate that the survival rate of gastroschisis is dependent on associated malformations and can vary between 80% and 88% (Tauriainen, 2023). The gastroschisis condition is usually diagnosed by use of antenatal ultrasound scans mostly around 18 to 20 weeks of pregnancy considering that the bowels can be seen outside the body ((NHS Foundation Trust, 2021). Additionally, some researchers estimate that roughly 10-15% of babies with gastroschisis have internal stenosis, malrotation, or atresia (Abdelhadi, El Dawy, & Ali, 2022). These and other similar studies justified the need to conduct a study on gastroschisis and some of the measures that can be taken to mitigate the psychological burden experienced by caregivers and mothers whose children are born with gastroschisis. Rentea and Gupta (2020) reported that roughly 10% of the cases of gastroschisis are usually linked with malformations outside of the gastrointestinal tract. Considering the different manifestations of gastroschisis, healthcare providers and other stakeholders need to take note of early symptoms of the gastrointestinal condition to provide timely medical attention to the affected persons.

Gastroschisis-related medical complications that manifest during childhood and growth have significantly remained a focal point in the previous nursing studies related to gastrointestinal complications. Reports from the National Library of Medicine (2023) indicate that children born with gastroschisis face a high risk of early mobility in life which affects long-term outcomes. Furthermore, gastroschisis has been linked to many childhood challenges such as growth failure as well as poor outcomes in educational performance (Strobel *et al.*, 2021; Elhassan *et al.*, 2022). Moreover, children diagnosed with gastroschisis might experience eating disorders and other gastrointestinal problems as they grow up. Such complications can necessitate the need for long-term treatment for constipation; while others might require long-term treatment for gastroesophageal reflux disease, also referred to as (GERD) (De Bie *et al.*, 2021; Veal, Overend & Crawford, 2022). Abdelhadi, El Dawy and Ali (2022) report that approximately 10% of the babies diagnosed with gastroschisis have associated congenital anomalies; apart from gastrointestinal

complications later in life. Subsequently, these other studies provide evidence of the need to provide interventions aimed at mitigating the complications and suffering of children diagnosed with gastroschisis as they grow up. Gastroschisis can also be manifested through paraumbilical which is associated with protrusion of the bowel through the defect (Ferreira *et al.*, 2022). Going by these manifestations, the stakeholders in the health sector must make an effort to reverse the incidences of gastroschisis which is at devastating medical condition.

From the empirical findings across African countries, gastroschisis continues to pose a significant challenge both from childhood and adulthood of the affected persons. Through a retrospective review conducted in Nigeria, Oyinloye *et al.* (2020) contend that within the context of Middle-income countries, the reported high mortality rates associated with gastroschisis are attributed to poor management rather than from limited resources. Through a prospective study conducted in Egypt, Shalaby *et al.* (2020) reported that one of the main challenges associated with instances of gastroschisis is infant mortality. Additionally, research conducted in the Ugandan pediatric unit indicated that mortality remains one of the key challenges in gastroschisis diagnoses and highlighted the importance of designing protocols that can reduce mortality associated with gastroschisis from 98% to up to 59% (Wesonga, Situma & Lakhoo, 2020). In Ghana, Abdul-Mumin *et al.* (2021) applied a retrospective review of gastroschisis methodology and referrals, with findings indicating that one of the kitchen inches of management of gastroschisis is poor referral systems and highlighted the significance of improved surgical care and peripheral systems as well as empowerment of community health workers in the efforts to reduce mortality rates associated with the gastrointestinal condition. Additionally, studies targeting sub-Saharan African countries comprising Kenya, Uganda, Tanzania and Malawi indicate that in most of the tertiary care facilities the survival from gastroschisis is less than 10% (Arivoli *et al.*, 2020). On the other hand, the mortality associated with gastroschisis in sub-Saharan African countries is between 75% to 100%, with Uganda reporting approximately 98% mortality among neonates diagnosed with the condition (Wesonga *et al.* 2020). Abrahams *et al.* (2024) recently conducted a 5-year retrospective survey in South African tertiary-level neonatal intensive care units on the surgical procedures conducted on children with gastrointestinal malformations, with the findings indicating a high level of post-operative survival amongst the infants with congenital surgically correctable malformations including gastroschisis. In essence, the research emphasized the importance of undergoing surgical operations as a way of correcting the malformations.

Adri *et al.* (2024) studied both the risk and prevalence factors of congenital malformation in Marrakech-Safi region of Morocco. Through a retrospective cohort study, the study findings revealed that some of the risk factors include chromosomal malformations, musculoskeletal defects as well as digestive tract defects. The writers also noted the fact

that it is critical to improve by identifying the risk factors early enough so that surveillance can be enhanced amongst populations at risk and come up with effective diagnostic, therapeutic, and preventive strategies. Fatona *et al.* (2023) report that an increasing prevalence of gastroschisis in SSA countries is primarily due to young maternal age. The birthplace prevalence of gastroschisis has increased dramatically in the recent past amongst countries in sub-Saharan Africa (Tiruneh *et al.*, 2022). In comparison to the Global North, it is apparent that most of the countries in the Global South are mostly vulnerable to the incidences of gastroschisis and therefore warrant additional measures and policy guidelines to curb the growing incidence of the condition. Within the tertiary health care institutions in South Africa's Eastern Cape Province, infant mortality resulting from gastroschisis remains a key challenge in pediatric health care (Machaea, Chitnis, & Nongena, 2023). Additionally, research targeting 67 hospitals in Malawi, Zambia, and Tanzania identifies surgical care as one of the key challenges associated with providing medical attention to neonates diagnosed with gastroschisis. In the efforts to improve in technology to scale down incidences of gastroschisis, Gannon *et al.* (2024) report on the development of algorithms aimed at improving neonatal resuscitation and stabilization especially those affected by gastrointestinal complications both in Malawian and Zimbabwean hospitals. Summarily, addressing the challenges associated with gastroschisis is important to provide optimal medical, diagnostic, and therapeutic care for the affected persons.

Distress and anxiety have been largely associated with the experience of the caregivers of these affected by gastroschisis. As observed by Roorda *et al.* (2022) increasing incidences of post-traumatic stress disorder (PTSD) amongst mother's caring for children affected by gastroschisis has been reported. Through qualitative interview studies conducted in Hospitals in England Wales and Scotland, Hinton *et al.* (2022) discovered that majority of the parents faced distress following diagnosis of their children with gastroschisis and urgently required emotional support. (Ferreira *et al.*, 2022). Additionally, formation of online groups was useful in terms of providing coping strategies and counseling services to the affected parents. Through a retrospective cohort study, Urichuk *et al.* (2024) report that mental health outcomes can be affected by the experiences of providing care for children diagnosed with gastroschisis. In other words, the mother's mental health status can negatively be affected by the experience of caring for their Children diagnosed with gastroschisis. Additionally, a research study targeting Dantec University Hospital Center in Dakar reflected on the challenges experienced in caregiving for neonates diagnosed with gastroschisis; especially the distressful experience of the mother's caregiving for the children affected by the condition (Camara *et al.*, 2024). In a study targeting patients admitted to Kenyatta National Hospital in Kenya, Thaiya, Dr Gachuri and Dr Bett (2023) provided evidence of the psychological effects felt by caregivers and mothers of neonates diagnosed with gastroschisis that warrant additional interventions for their quality of life to improved.

From the findings of earlier empirical research, various forms of support can be given to caregivers and mothers whose children are diagnosed with gastroschisis. Szydłowska-Pawlak *et al.* (2022) advocate for the need for consistent and comprehensive professional nursing interventions to ensure improved quality of life for the mothers and caregivers of children affected by gastroschisis. As a result of negative experiences experienced by caregivers of children diagnosed with gastroschisis, some researchers advocate for support in terms of the religious faith as well, and sharing experiences from parents whose children have also been affected by the condition can be a useful coping mechanism for the affected parents. Moreover, the authors also cite delayed initiation of medical treatment and shortage of mitigation as the thematic areas that underline the challenges experienced by the caregivers of neonates (Kidane *et al.*, 2022). Additionally, it is useful to institute mechanisms aimed at improving the quality of life of children who are diagnosed with gastroschisis (O'Brien *et al.*, 2022).

Gastroschisis-related publications from Kenya have consistently not adequately addressed the question of how the lived experiences of caregivers and mothers with neonates affected by the condition have developed coping mechanisms over time. In a study focusing on the transport and referral systems for patients diagnosed with gastroschisis, Gohil *et al.* (2023) identify the serious gaps in terms of pre-transit transit care of neonates affected by gastroschisis. Through a cluster randomized control trial using a case of patients in Moi Teaching and Referral Hospital (MTRH) proper transport systems for newborns with surgical conditions can be useful in improving the outcomes amongst children who are diagnosed with gastroschisis (Saula *et al.* 2022). Hetal (2022) provides an assessment of the neonatal transport and referral system for the patients affected by gastroschisis. The majority of the focus of such studies was on transport systems for Neonates affected by gastroschisis. The foregoing studies did not focus much attention on addressing the lived experiences of the mothers caring for their neonates diagnosed with gastroschisis; which informs the objective of the current research with the motivation to fill the empirical research gap as well as provide recommendations to the practitioners caring for the children affected by this congenital condition.

Materials and method

Setting

This study was conducted at Kenyatta National Hospital in Nairobi, Kenya. The hospital is situated approximately 3.5 kilometers from the Nairobi city center. Being a National Referral Hospital, the facility is well-resourced with the personnel and equipment that provide a wide range of critical care services to patients with different medical complications. The choice of this hospital facility is based on the fact that it has been at the forefront of providing medical and clinical interventions for neonates affected by

gastroschisis and related complications. In particular, the hospital has Ward 4A, which is a pediatric surgical ward with a neonatal unit and a Newborn Intensive Care Unit where neonates diagnosed with gastroschisis medical condition are admitted. Ward 4A has a 32-bed capacity while the Newborn Intensive Care Unit has a 7-bed capacity both of which have a monthly occupancy rate of 90% and 71% respectively.

In addition, the hospital has the Surgical Outpatient Clinic (Number 23) which is mandated to follow up on the neonate's well-being after being discharged. The clinic is conducted routinely every Thursday between 0800 hours and 1300 hours. and neonates who need to attend the clinic are booked beforehand, with a monthly average attendance of neonates of approximately 100(one hundred) newborns. Subsequently, the researcher's choice of the KNH facility is justifiable based on the presence of relevant human and physical resources that are aimed at providing optimal care for the children diagnosed with gastroschisis; therefore, would help gather the relevant data that will be useful in answering the questions of the research posed at the beginning of the current research.

Study design and sample

The current research was anchored on the phenomenological research design, which is useful in capturing the study participants' lived experiences (Heimann *et al.*, 2023; Ajjawi *et al.*, 2024). The researcher aimed to understand and describe the experiences of the mothers in terms of the support they are given as they take care of their neonates affected by gastroschisis.

Phenomenology can be implemented using a various approach in the collection of relevant data; for instance, using interviews, participant observation as well and analysis of personal texts. Some researchers advocate for the use of interviews as the best approach to answering research questions in phenomenological studies. Additionally, making use of observations can help test the hypothesis in phenomenological studies (Klinke, & Fernandez, 2023). Larsen (2023) contends that the analysis of textual information from phenomenological studies is useful in answering the stated research objectives.

The researcher therefore selected to use one-on-one interviews, facilitated by the use of interview guides administered amongst mothers of neonates born with gastroschisis which is a medical condition. Moreover, one of the strengths of the phenomenological approach was that the researcher was not relying on prior knowledge of gastroschisis; but rather was relying on information given by the mothers of the neonates admitted in the KNH hospital. This study utilized a purposive sampling method where all respondents with the required phenomenon of interest were included in the study. This method is used for the selection and identification of information-rich cases related to the phenomenon of interest (Sarna, 2017). For the mothers in the NICU, the interviews were conducted in the Ward 4A

playroom. In addition to purposive sampling, there was criterion sampling as the study used phenomenology where the predefined criteria were delivery of a neonate with gastroschisis. Though the caregivers and mothers identified were having a shared experience, their characteristics were different. (Mosera & Korstjens, 2018).

Data collection tools and procedures

Firstly, this study took the step to identify caregivers and mothers whose neonates were born with gastroschisis and were admitted to the Newborn Intensive Care Unit (NICU). As part of the research ethics, informed consent was given to the mothers by informing them about the nature of the study, its goals, and what was required of them during the study. I informed them that participation in the study was purely voluntary, and therefore allowed them to opt out of the study at any time. The second step focused on the collection of relevant data. To achieve this, the interview guides were used to implement one-on-one interviews that were conducted over a period of 2 months. In the instruments of data collection, this study focused on asking general questions relating to their experiences about caring for neonates with gastroschisis. The responses from the caregivers and mothers were recorded using a notebook and a pen, as well as a tape recorder that was useful in recording the feedback from the mothers for future reference and analysis. The result was collection of the bulk of textual data ultimately provided an understanding of the common experiences of the participants. These responses were therefore recorded in a journal and audio taped for analysis. Subsequently, the information was coded and developed into themes in readiness for qualitative analysis.

Data management and analysis

Data management was done through a filing system that was developed for handwritten notes and voice recordings. A master list of types of information was gathered and backup copies were developed. The researcher was protecting the anonymity of participants by masking their names in the data. A data matrix was developed as a visual means of locating and identifying information for the study. A manual process was used in the analysis of qualitative data from the interviews. The transcription from the interviews was useful in enabling the researcher to highlight significant statements that provided an understanding of how participants understood the phenomenon. Themes were developed from the clusters of statements and thematic analysis was done inductively. Themes were used to write a description of the context that influenced the participant's experience of the phenomenon (imaginative variation). The researchers were able to reflect on these personal statements at the beginning of phenomenology.

From the textural and structural descriptions, the researchers were able to write a composite description presenting the essence of the phenomenon. This enabled the researcher to focus on the common experiences of the participants, meaning all experiences have an underlying

structure. From this descriptive passage, the researcher was able to commit away from the phenomenology with the feeling and understanding as to why the participants felt the way they did. This enabled the researcher to create a research journal. The collected data was then retrieved and generated into themes and subthemes and then analyzed. This led to fundamental structuring, leading to the meaning of experiences as narrated by the participants (Dye, 2021).

Table 1. Individual case categories

Individual case category	<i>n</i>	%
Prenatal diagnosis	1	0.6
Postnatal diagnosis	24	13.6
inpatient	25	14.2
Financial strain following diagnosis	15	8.5
Adequate care from nurses	23	13.1
Adequate emotional support from the family	23	13.1
Adequate finances available for surgery	10	5.7
Access to spiritual support	15	8.5
Access to social support	15	8.5
Mental symptoms following diagnosis	25	14.2

Results

Introduction

The mean age for caregivers and mothers was 26 years and the neonates was 15 days. With the neonates having an average weight of 2.6 kgs. Eight mothers out of the 25 respondents were earning an average income of Ksh 32, 500 per month. Twelve mothers were married out of the sampled population. Twenty-four of the 25 respondents have at least acquired basic education with 8 mothers having acquired university education, Table 1. Table 1 summarizes the characteristics of mothers.

Table 2. Mothers' Characteristics

Characteristics of mothers	Findings
Average age	26 years with a range of (20 years-36 years)
Average age (neonates)	15 days with a range of (14-16 days)
Average weight (neonates)	2.6kgs, with a range of (2.4kg-2.8kg)
Employed	8 mothers
Average income	Ksh32,500
First time delivery	12 mothers
Married	21 mothers
Basic education (Primary)	Primary-9
Access to social support	Secondary-10
Mental symptoms following diagnosis	University-6

Main Theme: Support Systems for the Mothers

Family members provided emotional support to the mothers as they were in constant and regular communication with the sampled mothers. This was also complemented by the fact that the admitted mothers with similar conditions in the ward discussed amongst themselves and encouraged each other. They also prayed together in the morning and the evening. The mothers also recommended the staff share information concerning their neonates, especially the doctors and the nurses. Other hospital staff were also kind to the mothers; especially the catering services as they served them with meals.

The physical environment around the mothers was also conducive. The public health services were particularly good with high standards of cleanliness maintained especially in the neonatal wards. The public health officers also went an extra step to teach the admitted mothers about infection preventive measures. The officers also expressed concern over congestion, considering that mothers had to share beds due to a high number of admissions of neonates suffering from different conditions.

Table 3. Summary of Main Themes and Subthemes Related to Support Systems

Objective	Theme	Subthemes
To explore the support needed by mothers of neonates admitted to the NICU at KNH	Healthcare provider family support system	(a) Healthcare provider’s support (b) Hospital environment (c) Physical space adequacy

Following the overarching theme of support system from the healthcare providers and family members presented in *Table 3*, and respective subthemes, the discussions about the current research will be split into three subthemes as follows:

Subtheme 1— Healthcare provider support

The current research’s third objectives were aimed at identifying gaps in the care given in order to improve the care of mothers whose neonates are born in KNH. In order to meet this objective, a series of questions were asked: Is adequate emotional support given? Respondents noted that they had received sufficient emotional support from the professionals at KNH, particularly the nurses who attended to their neonates. The results indicated that they felt they received adequate emotional support during their stay at KNH. “The nurses are extremely kind and will help you whenever you want them to. Besides being incredibly supportive of me, the other moms who have children in the same ward have been encouraging.”

As F5 (23 yrs) stated,

“While in hospital X, at the time of delivery, the doctors around had ~~delegated~~ their work to student nurses and did not know how to handle the situation.”

“While at Kenyatta National Hospital, I have gotten adequate emotional support from the medical personnel.”

F17 (29 yrs) states that,

“While in hospital Y, I was given counseling at the health facility where I delivered.”

Everything provided to them at KNH has been of high quality, and they received adequate emotional care here. Respondents had not been involved in any conflicts throughout the time. KNH provides adequate emotional support, particularly through the nurses.

The next question was based on KNH’s commitment to the provision of care, and most respondents stated that when one considers KNH a public institution, one cannot be amazed by the staff’s degree of dedication, especially given the circumstances. Their neonates received excellent care, and they were quick to respond to any inquiries they had about the

situation. Nonetheless, some interviewees stated that KNH staff commitment is not 100% as they sometimes neglect them. This is in line with F11 (33yrs), reported that,

“I would rate the staff commitment at 70% overall. The nurses should improve since mothers are sometimes left to tend to their babies on their own”

F22 (29 yrs.) noted that,

“Some doctors explain the condition to you and the surgery that they will conduct...”

The next aspect was to determine if surgeries were scheduled; most sampled mothers stated that their babies had been to the theatre once, and the surgery was done as scheduled. Operations may sometimes be rescheduled, but the changes are very slight. All the procedures were done as scheduled as nurses and doctors were very keen on the details and ensured that they offered comprehensive services to patients.

Subtheme 2—Hospital environment

Positive relationship between the parent and Health care providers. Regarding the relationship between patients and staff, most interviewees stated that they had a healthy relationship with Kenyatta National Hospital. As F15 (31 yrs) stated,

“The staff in the department are very nice. The nurses are supportive and give reassurance at all times. The doctors are also very good to me. I am satisfied with the kind of care I receive here at Kenyatta National Hospital.”

It is believed that the establishment of a high-quality nurse-patient relationship is necessary to ensure efficiency. This is because it helps to facilitate efficient communication between the healthcare team and the patient, which, in turn, contributes to improving the client's condition and overall well-being.

According to the results, the connection between the patient and the physician is the cornerstone of clinical treatment. Relationships between a patient and a physician may have significant negative and positive repercussions on clinical treatment. In the end, the main purpose of the connection between a patient and a physician is to enhance the patient's health status and the medical treatment they get. There is a positive correlation between stronger patient-physician connections and higher patient outcomes.

Understanding the elements affecting the connection between a patient and a physician is necessary in light of this interaction's growing significance. It has been demonstrated that effective communication between patients and physicians positively influences health consequences by increasing the satisfaction of patients, resulting in increased family knowledge regarding health problems and the therapies available, contributing to better compliance with treatment proposals, and providing patients with support and affirmation.

Subtheme 3—Physical space adequacy

From the findings, the question of adequate space needs to be addressed to create a conducive environment for the medical staff and caregivers of neonates diagnosed with gastroschisis. In this regard, Doctors need to refrain from delegating their duties in situations like these. These are the things that happened to the participants in Hospital X. It seemed as if the nurses working there were unfamiliar with what was happening. The study found that some participants felt that KNH should strive to get more beds for the mothers so that each mother is comfortable. The mother's comfort contributes to their mental well-being.

Discussion

The study showed that they had received sufficient emotional support from the professionals at KNH, particularly the nurses who have attended to their newborn children. Health practitioners often have to give negative news, but there were several instances of outstanding practice in successfully addressing this situation. These encounters were distinguished by the fact that information was provided to parents straightforwardly and understandably, occasionally supplemented by the drafting of graphics, however, without resorting to condensation or “dumbing down.” Parents were grateful that the medical staff took the time to respond to their concerns and did not make them seem as if any of their inquiries were in any way insignificant. The help that parents obtained from various sources was seen as typically beneficial by these parents. There is improvement in the quality of life of the caregivers and mothers of children affected by gastroschisis, especially through being provided with adequate support (Szydłowska-Pawlak *et al.* 2022).

Throughout the past few years, healthcare professionals and scientists in the health-service industry have come to a greater realization that to improve the quality of Care and consequently improve patient outcomes, a method is required that, first and foremost, focuses on understanding the patients' perspectives (Wright *et al.*, 2015). On the other hand, most mothers have described encouraging significant experiences concerning their interaction with HWs. Mothers had also described feeling contented that their babies were receiving adequate Care whenever they were provided with information regarding the health and advancement of their baby because nurses started listening to their worries, and when nursing staff conveyed information to them in a pleasant and considerate manner. These findings therefore collaborate with suggestions by O'brien *et al.* (2022) on the importance of instituting mechanisms of providing support for the caregivers of children affected by gastroschisis.

According to the research findings, there is an efficient communication flow between nurses, mothers, and other healthcare professionals. This contradicts the findings of a

preceding study conducted in a South African neonatal intensive care unit which found inadequate communication. That study found that healthcare workers frequently made unilateral clinical decisions for parents, even though parents desired to participate in the decision (Almeida *et al.*, 2016). HWs, especially physicians, are often in the driver's seat when it comes to decision-making, and they may not have complete faith in the capacity of mothers to make well-informed choices (Almeida *et al.*, 2016). As a result, healthcare workers (HW) need to conduct an in-depth self-examination to determine how seriously they take the involvement of patients in the life-altering choices made in the newborn unit. It has also been proven that home health assistants have poor communication skills. If there is a movement toward more respectful treatment, home health aides need to strengthen their interpersonal and communication abilities. It can therefore be said that training may help strengthen a person's communication and counselling abilities; obtaining this education should be a priority for HWs assistants in the new-born unit.

This study found that nurses at KNH are committed to taking Care of patients and meeting their goals. As such, the relationships between a patient and a physician may have significant negative and positive repercussions on clinical treatment. This collaborates with the findings of Dekel *et al.* (2017). They came to the view that nursing care encompasses not only the management of diseases but also the promotion of patients' comfort and the acknowledgment that the patient's well-being also includes aspects of their mental, interaction, and spiritual lives. Nurses are equipped with the information and skills necessary to alleviate symptoms and other unpleasant manifestations for patients with severe or life-limiting illnesses, as well as to collaborate with patients and their families in decision-making about compassionate and end-of-life care. Contrary to other studies where mothers of neonates with congenital anomalies are stigmatized (Kidane *et al.*, 2022), this study's findings showed that the spouses and close family members gave support. They also got peer support among themselves. This gave the mothers a sense of hope. Overall, it can be said that most of the findings from the current research align with what was proposed in earlier empirical studies, especially regarding the aspect of providing adequate support for the caregivers of children diagnosed with gastrointestinal malformations such as gastroschisis.

Conclusions

Based on the results, the study concluded that Prenatal and Postnatal Experiences of Mothers with children with gastroschisis had a positive experience. Most sampled mothers were happy that they were pregnant and were ready to follow doctors' guidelines throughout the period. During ANC the anomaly was not diagnosed. The nurse's service quality was good and successful as they guided the mothers in pre and postnatal care. Post-Nataly, the mothers experienced various mental challenges due to inadequate support from

close family relatives and inadequate information about the condition before delivery. They were unprepared to deal with the difficulties and stress related to the neonate's condition. This study also concluded that caregivers and mothers with children with gastroschisis experienced various mental challenges due to inadequate support from close family relatives. The caregivers and mothers were not given any warning or information about the condition before their children were born, so they were unprepared to deal with the difficulties and stress related to the children's disease. Prior counseling and knowledge could have reduced the mental symptoms and also prepared them to handle the situation. In conclusion, some of the nurses working did not have any knowledge of gastroschisis. According to the data given by the caregivers and mothers of neonates, the nurses attending to them had inadequate knowledge of how to handle the condition.

The adequacy of the available facilities to accommodate the mothers and neonates diagnosed with gastroschisis was a challenge. Additional beds should be made available for post-natal caregivers and mothers to ensure comfort to them. Comfortable accommodation would ensure that caregivers and mothers are relaxed when they are not tending to their neonates therefore reducing emotional trauma.

Recommendations

A more thorough prenatal screening is recommended to assist in the early detection of such congenital disorders, which can direct birth preparations for the mother and child. In this regard, The World Health Organization recommends at least one ultrasound during the first trimester.

Healthcare providers should consider the mental health of the caregivers with neonates born with congenital anomalies rather than concentrating on the neonates alone. To assist in easing the mental and emotional strain placed on parents, hospital staff should provide professional counseling. They should also encourage peer counseling among mothers.

The findings of the study could provide information that services, program managers, and policymakers can use to design therapeutic actions that can improve both the overall experience that families and their patients have and the quality of the services provided to them. The findings of the research have the potential to be used as a benchmark, and the implications of the findings may be applied to a variety of other pediatric surgical procedures.

It is possible that further research on the experiences of mothers whose families did not make it through the illness would provide more understanding of how the quality of gastroschisis services might be improved.

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