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PSYCHOLOGICAL EFFECTS EXPERIENCED BY MOTHERS WHOSE NEONATES ARE ADMITTED IN NICU AT A NATIONAL HOSPITAL WITH GASTROSCHISIS: A PHENOMENOLOGY STUDY

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ABSTRACT

Background: Gastroschisis is a rare congenital condition that occurs while a fetus is in the early stages of development that results in the abdominal wall having a protrusion of abdominal contents – small and large intestines and the stomach. Delivery of a neonate with chronic illnesses like gastroschisis greatly affects mothers and caregivers because neonates who do not receive surgical care immediately after delivery end up losing their lives, while those who do survive require extensive medical care that requires additional hospitalization and comprehensive care which many parents are unsure how to provide or able to afford.

Broad Objective: To explore the psychological effect exhibited by mothers whose neonates are admitted in Neonatal Intensive Care Unit (NICU) in the Kenyatta National Hospital with gastroschisis.

Methodology: A qualitative study guided by descriptive phenomenology was conducted. In-depth-interviews with twenty-five (25) mothers purposively sampled, Interviews were audiotaped, the data later transcribed inductively analyzed into themes and sub themes.

Findings: Two themes were developed first, Stages of grieving. Some mothers experience shock when they saw the condition of the neonates with denial feeling that what they were seeing was not real. They felt angry with God and bargained on the same hoping that things would change. The mothers went into depression and finally accepted their situation as they came to terms with reality. The second theme was mental health issues: in this case, admission of the neonates in NICU caused mental negative psychological effects to the caregivers. They suffered separation anxiety from other family members. There was delegation of roles at home as some had other children. There was fear of stigma and lack of support from the families. In NICU, caregivers received peer support from themselves as they shared different experiences.

Recommendations: Concerted efforts by the stakeholders in the Healthcare sector are necessary in order to alleviate the negative psychological effects felt by mothers of children born with gastroschisis.

Key words: Neonates; Gastroschisis.

INTRODUCTION

Globally, projections indicate a rising incidence of gastroschisis, with the United States experiencing a 300% increase between the years 1998 and 2013 (Clark *et al.*, 2020). In Canada, information from the Canadian Institute for Health Information reported a gastroschisis prevalence rate of 3.7 per 10 000 total births in 2006 and 3.4 per 10 000 total births in 2017 (Liu *et al.*, 2021). In addition, empirical studies from the Brazilian state of Rio Grande reveal that between the year 2000 and 2017, the number of 2,612,532 live births, out of which there were 705 hospitalizations due to gastroschisis (Egger *et al.*, 2022). As a medical intervention, surgical procedures to correct gastrointestinal anomalies have widely been publicized in research

Gastroschisis is defined as the herniation of midgut bowel into the amniotic cavity through a paraumbilical full-thickness wall defect, most commonly to the right of the cord insertion (Aboughalia *et al.*, 2020). Gastroschisis can also be defined as a congenital anomaly where there is an abdominal wall defect leading to bowel evisceration (Negash & Temesgen, 2022). Further, Gastroschisis is also defined as an abdominal wall defect to the right of the umbilicus with exposed abdominal contents lacking an overlying covering (Mowrer, DeUgarte, & Wagner, 2022). On the other hand, Laezza *et al.* (2022) define gastroschisis as a right sided periumbilical wall defect with herniation of abdominal structures that float freely in the amniotic cavity.

Research across different countries provides evidence of the need to address gastrointestinal anomalies amongst infants. Reports from the US suggest that 2006- 2010, there was a total of 3439 cases of gastroschisis among 8,342,741 live births, while the Year 2011-2015 saw the rise of these number to 4166 out of 9,359,005 live births (Short *et al.*, 2019). Raitio *et al.* (2020) analyzed the prevalence of gastroschisis in Finland between the years 1993 and 2014. Through a population based nationwide study, data was extracted through both Finnish register of congenital malformations as well as Care Register for Healthcare for the years 1993 to 2014 including life births. The information on anomalies was captured and analyzed accordingly. Based on the sampled responses, the findings showed that 235(73%) of respondents reported instances of gastroschisis. The study findings also revealed that babies with gastroschisis were born prematurely on average on the 36th week and delivered by Cesarean section.

In Africa, there has been growing scholarly evidence on the medical challenge posed by gastrointestinal complications amongst infants. Gom, Grieve, and Velaphi (2019) analyzed survival rates amongst neonates in developing countries. Data collected from hospital records of neonates with the gastroschisis in Johannesburg South Africa between the years 2009 and 2016 indicated that complex gastroschisis was found amongst 36.3% of the cases with majority who required staged reduction. Moreover, Tiruneh *et al.* (2022) conducted a study to assess the prevalence of the burden of gastroschisis in Sub-Saharan Africa. Data reviewed from three databases comprising PubMed, Cochrane library and Google scholar. From the study findings, the pooled prevalence of gastroschisis among congenital birth defects in Sub-Saharan Africa was found to be 3.22% (95% confidence interval). Considering the high prevalence rate of gastroschisis in Africa, the authors recommend the need to have perinatal screening programs for congenital anomalies.

As a result of gastroschisis diagnosis amongst their children, many parents face emotional distress in the wake of this realization. This is an agreement with Roorda *et al.* (2022) who argued that increased distress and post-traumatic stress always exhibited amongst parents whose children were diagnosed with gastroschisis. This line of argument is corroborated by Oftedal *et al.* (2022) who observed that parents whose children were diagnosed with severe gastroschisis experienced elevated symptoms of stress and trauma in comparison with those with least severe diagnosis amongst their children. Other than emotional distress in the trauma, the challenge of stigmatization from society was also yet another experience of parents of children affected by gastroschisis. This corroborates studies outlining the fact that stigmatization is one of the key challenges experienced by mothers of children diagnosed with gastroschisis (Fisher *et al.*, 2022). Additionally, the study results are similar with recent findings by Leraas (2023) who took note of the fact that parents whose children were diagnosed with gastroschisis always faced stigmatization in the community. Subsequently, these and other similar findings provide evidence of the emotional challenges faced by parents whose children were diagnosed with gastroschisis.

Against the backdrop of the foregoing challenges, the present study analyzed the lived experiences of mothers with neonates affected by gastroschisis particularly by narrowing down to emotional effects and feelings of guilty, stigma and spouses support as well as family reaction on learning that their children were diagnosed with gastroschisis. This was achieved by anchoring the study on theoretical postulations of Middle-range Nursing Theory of Uncertainty for which explains how individuals directly affected by chronic illnesses develop their positive or negative coping mechanisms in the new situation that is marked by uncertainty. In this regard, positive and uncertainty is seen as an opportunity to overcome the illness and fully recover, while negative uncertainty is associated with danger. The theory therefore revolves around three major antecedents of uncertainty which refers to the mother's experiences before illnesses defined as stimuli frame.

MATERIALS AND METHOD

Setting

The study was conducted at a National Hospital in Nairobi, Kenya. The hospital is situated approximately 3.5 kilometers from Nairobi city center. The hospital is well resourced with personnel and equipment to provide a wide range of critical services to the patients. The hospital has been at the forefront of providing clinical and medical intervention for neonates affected by gastroschisis. In this regard, the hospital has a bed capacity of 2500 patients where approximately 15 neonates affected by various gastrointestinal complications are attended to at the facility on a monthly basis. In addition, there is need for research that sheds insights on the experiences of mothers in Kenya whose neonates are diagnosed with gastroschisis to provide context-specific recommendations because their experiences vary greatly from those of their peers in the United States and other developed countries.

Study design and sample

This was a qualitative study which was conducted using a phenomenological approach. The approach was useful in capturing the lived experiences of the study participants. The rationale for conducting the present study was to analyze psychological effects exhibited by Mothers whose Neonates are Admitted in NICU in a National Hospital with Gastroschisis. Data was collected using introspective interviews administered amongst twenty-five (25) mothers of neonates with gastroschisis. Data was captured using this process of facilitated vivid and clear description of the experiences of mothers whose neonates were born with gastroschisis. The interview questions were centered around the experiences of mothers when giving care to these children. The interview transcripts were audiotaped and transcribed afterwards. This was followed by a thematic analysis manually in order to unveil overarching themes relating to the mother's experiences.

Data collection tools and procedures

Data was collected through multiple in-depth interviews from mothers to capture information on variables of interest on their experiences as caregivers of neonates with gastroschisis. Participants were asked broad general questions of their experiences in terms of the phenomenon. This was followed by a data gathering process which led to a textual and structural description of experiences and ultimately provided an understanding of common experiences of the participants. They explained the contexts that had typically influenced their experience. Data collected went through interview transcriptions and highlights of significant statements that provided an understanding on how participants experienced the phenomenon of interest. The responses from the mothers were recorded in a journal and audiotaped for the purposes of analysis Themes were generated from significant statements. These significant statements and themes were used to write a description of what the participants experienced [textural description]. They were also used to write a description of the context that influenced the participant's experience, the phenomenon [imaginative variation] and reflected these personal statements at the beginning of the phenomenology. To ensure trustworthiness, data analysis was done in a manner that would ensure consistency and auditability. Ethical issues were considered in the study. Prior to data collection, the researcher sought permission from the Ethical Review Committee. Following the approval, permission was sought from the Research Department at Kenyatta National Hospital to conduct the research. The respondents were asked to participate in the study voluntarily. Moreover, privacy and confidentiality of the information provided was assured to the respondents. Additionally, the respondents were asked to give written consent requiring them to withdraw from participating in the study at any point.

Data management and analysis

The process of transcribing collected information was undertaken immediately after completion of a data collection exercise. As a means to triangulate the information given by the respondents, the researcher took an extra step to verify the information by getting additional information from the hospital staff. The first step during coding of the material was to open a code book, where initial information sourced from the interview transcripts was captured by the researcher. The coded material was reviewed and revised several times by the researcher prior to deciding what to capture for further analysis. This process conformed to the widely acknowledged procedure for reporting qualitative results. Relevant verbatim were captured from the transcripts for the purposes of illustrating and underscoring the important thematic areas relating to the study data was analyzed manually.

RESULTS

Introduction

This section presents the findings of the study relating to their mother's experiences of caregiving for the children affected by gastroschisis. A combination of descriptive and thematic analysis were applied in answering the overarching research questions of the study.

Demographic characteristics of the caregivers

Respondents demographic characteristics were analyzed to have an overview of the underlying attributes of the caregivers. This was accomplished through use of frequencies and measures of central tendency. From the findings, it was established that the mean age for caregivers was 26 years. The mean age of the neonates was 15 days, with an average weight of 2.6 kgs. Eight caregivers out of the 25 respondents were earning an average income Ksh 32, 500 per month. Twelve caregivers out of the sample population were married. Twenty four out of the 25 respondents have at least acquired basic education with 8 caregivers having acquired university education (Table 1).

Table 1. Characteristics of the caregivers

Caregivers	Infant Age (Days)	Infant Weight (Kgs)	Income (Ksh)	Parity	Marital Status	Highest Education Level Attained
F1 (24 yrs)	14	2.6	Unemployed	2	Married	Primary School
F2 (28 yrs)	14	2.8	Unemployed	1	Married	N/A
F3 (30 yrs)	16	2.9	50,000	2	Single	University
F4 (24 yrs)	15	3.0	Unemployed	1	Married	Primary School
F5 (23 yrs)	14	2.4	Unemployed	1	Married	Primary School
F6 (30 yrs)	14	2.6	15000	3	Single	High School
F7 (27 yrs)	14	2.5	Unemployed	3	Married	High School
F8 (20 yrs)	14	2.6	Unemployed	1	Married	High School
F9 (22 yrs)	14	2.5	Unemployed	1	Married	High School
F10 (24 yrs)	16	2.6	Unemployed	1	Married	High School
F11 (33 yrs)	16	2.5	Unemployed	4	Married	University
F12 (20 yrs)	14	2.5	Unemployed	1	Married	High School
F13 ((23 yrs)	16	2.4	10000	2	Married	High School
F14 (27 yrs)	16	2.8	40000	3	Married	University
F15 (31 yrs)	14	2.7	50000	4	Married	University
F16 (26 yrs)	15	2.6	Unemployed	2	Married	High School
F17 (29 yrs)	14	2.7	10000	2	Single	High School
F18 (26 yrs)	16	2.5	30000	1	Married	University
F19 (34 yrs)	14	2.8	40000	3	Married	University
F20 (21 yrs)	14	2.6	Unemployed	1	Single	High School
F21 (23 yrs)	14	2.7	Unemployed	1	Married	High School
F22 (29 yrs)	15	2.8	35000	2	Married	University
F23 (36 yrs)	16	2.8	45000	4	Married	University
F24 (21 yrs)	14	2.5	Unemployed	1	Married	High School
F25 (23 yrs)	14	2.8	Unemployed	1	Married	High School

Thematic Analysis

Thematic analysis was necessary in order to unravel important thematic areas related to care giving for children affected by gastroschisis. The identified themes were described as follows:

Theme 1: Emotional Effect and Feelings of Guilt.

Information given by the respondents revealed emotional effect and the feelings of guilt on the side of The Mothers of neonates diagnosed with gastroschisis. This was due to the fact that a mother's mental health and general quality of life can be negatively impacted due to having a preterm infant and the experiences of being in the neonatal intensive care unit (NICU). Whenever a parent finds out that their unborn baby will need an operation, it may have a significant emotional effect on them throughout their pregnancy, while they are in the hospital after the baby is delivered, and after they return home with their new family member. The majority of the participants felt extremely lonely throughout their time spent away from the family with the baby. Majority of the mothers reported suffering from anxiety, panic disorder, and loss of memory, while others said that they had feelings of guilt. Some of the mothers were prescribed antidepressants and provided counseling services. In addition, expressions from the fathers suggested that they were in a state of shock following what they had observed from the neonates.

As F1 (24 yrs.) indicated,

"I was traumatized by the situation since I had never experienced something like this." (A 24-year mother of one of the infants).

"When I was shown my baby by the nurse while in the labor ward, I was shocked and confused as I had never seen such a condition all my life."

Based on the above response, it was apparent that the experience of caring for the children affected by gastroschisis had an emotional and traumatic impact.

Theme 2: Stigma and spouse's support

The health of their innocent fetus is the primary thing most expecting parents are concerned with. During the prenatal stage is often when parents get the devastating news that their unborn child will have a birth defect. They can get so focused on their baby's medical state and the visits to the doctor's that they do not enjoy their pregnancy. Some mothers are so anxious about the after-effects of giving birth that they do not even prepare adequately due to fear of the outcome. It might be helpful for these parents to take some time to relax and allow themselves to feel "normal," but doing so is often quite challenging for them. They worry about how the future will be like having a baby who has a birth defect.. During this period, parents often have to make many challenging choices and want reliable and precise information. Empathy, love, and engaging with those who have walked a similar route(peer) may also assist greatly, particularly for parents going through this difficult period.

The participants were asked who took their responsibilities at home when they were admitted. Most mothers interviewed expressed that they were helped by their husbands, who stood in for them and even gave them words of encouragement. As noted by F12 (20 yrs.)

"My husband has since taken over my responsibilities at home. He is taking care of our other children."

However, some participants noted that they were not supported by anyone at home, as F3 (30 yrs) stated,

"There is no one to take over my responsibilities at home. My sister is still dependent on me, and even as I am in the hospital, I have to ensure that she has enough finances to sustain herself until I am discharged. We have no one else to call family."

Many parents feel alone in their daily lives, especially if the birth defect their neonate is born with is uncommon, and there is no assistance available. This may lead to severe depression that can drive troubled parents to withdrawal since they feel "different" from their friends, which can raise the likelihood that they will experience further sad or mental health agony. Parents who have children who require multiple treatment methods or have different disabilities due to a birth defect believe in further isolation from their peers because they have so little in common with their colleagues when it comes to raising their children because they face so many unique challenges. Daily activities like going to the park may be challenging for families with children with birth abnormalities because the physical disparities between healthy kids and those with birth problems are more obvious when the children are close to one another.

Theme 3: Family reaction

Reaction of the immediate family members upon seeing the newborn baby was yet another important thematic area in the current study. Based on the results, it was revealed that both their husbands and other family members were very supportive, whereas some stated that they were neglected, and no one wanted to relate to or associate with them. A number of the parents in the hospitals with their children mentioned how they experienced isolation, and how it influenced their psychological well-being. The results show that emotional assistance from relatives and friends was crucial for parents to maintain sanity throughout the period of hospitalization. The majority of respondents placed a high priority on both the psychological and practical assistance that their families provided for them. It was helpful that they could do fundamental things for them, such as giving them food and clean clothing and emotional support.

Discussion

According to the findings, some parents had a diagnosis made during prenatal scans, while others had no idea until after their neonate had been delivered. There must have been more negative psychological effects for mothers whose diagnosis was made prenatally, but then it had an advantage since they were advised on birth. plan on where to deliver their neonates. This corresponds with the study on primary closure of gastroschisis aided by ileostomy (Negash & Temesgen 2022).

Irrespective of when the diagnosis was made, it proved a great deal of difficulty for the parents of a child who would need abdominal surgery considering the age of the neonates. Most of the mothers were uncertain about the expected outcomes of the surgeries. The care procedures for these babies as stipulated by the work instructions were difficult for the mothers of neonates to understand. It was quite normal for them to have setbacks. Some professional personnel could not give assurance to parents. As a result, there was a significant amount of both practical and emotional unpredictability. At every age, parents are challenged to learn to adapt to a life filled with uncertainty and fear. Several parents expressed persistent sadness and concern (LoBiondo-Wood, 2014).

According to the research findings, having a child with congenital anomalies and the experiences of being in the neonatal intensive care unit may significantly influence a mother's mental health and overall quality of life (NICU). In addition, the researcher found that when a parent finds out that their unborn child will need surgery, it may have a serious emotional effect on them throughout the pregnancy period, when they are in the delivery room after the baby is delivered, and after they go home with their new-born. Most mothers with neonates experienced pain from nervousness, anxiety attacks, and loss of memory. These findings align with the study drawn by Hug *et al.* (2019), who found that most mothers with newborns developed distress from anxiousness, panic disorder, and memory loss.

According to the research findings, the anxiety and difficulties the parents faced started when their children were born with the condition, even though they had no previous warning or opportunity to plan for it. Furthermore, the difficulties continued after the patient was discharged from the hospital. The parents, in general, were thankful for the Care and attention they had gotten from the various medical professionals. When their children are hospitalized in neonatal intensive care, their mothers encounter several psychological obstacles as they try to find a place for themselves in the hospital settings with medical complexities including critically sick children (Hug *et al.*, 2019). According to Kuremu *et al.* (2017), premature infants need specialized Care, which may include hospitalization immediately after birth. Pregnant women who deliver their kids prematurely may have to remain in the hospital for an extended amount of time and may have increased anxiety over their infants' prognosis and course of treatment. Most parents could find these situations to be distressing. In line with similar research findings, the parents who participated in our survey expressed gratitude for the medical treatment their children had received (Hug *et al.*, 2019).

The medical professionals responded promptly by referring the neonates to a major health facility. Treatment was initiated immediately leading to survival of the neonates. Despite this, they were required to find a way to deal with the circumstance. According to (Kuremu *et al.*, 2017), Mosera & Korsten's, 2018) demonstrate that the support HWs offer is generous in dealing with the discomfort and anxiety experienced. On the other hand, participation in the Care of the infant boosts a woman's self-esteem, gives her more control over how she interacts with her surroundings, reduces feelings of worry, and helps her feel more confident in her role as a mother all of which supports bonding. HWs can provide knowledge, support, and direction and actively foster confidence in the relationship with the newborn infant. It is essential that HWs actively encourage mother-baby bonding and consider this as a crucial role in their work. Doing so may have long-term advantages for the well-being of both the mother and the infant;

therefore, HWs must strengthen the mothers' confidence and include them in the care of the babies.

The study findings are similar with what was observed in an earlier empirical study by Roorda *et al.* (2022) whose study focused on distress and traumatic stress amongst parents of patients with congenital gastrointestinal malformations. Through a cross-sectional cohort study, it was found out that the prevalence of post-traumatic stress disorder (PTSD) was significantly higher amongst mothers (23) compared to the reference group. These findings were collaborated in the present study considering that majority of the sampled mothers experienced cases of trauma upon learning that their infants were diagnosed with the gastroschisis. ,The study findings were in agreement with what was established by Oftedal *et al.* (2022) whose study revealed that parents whose children were diagnosed with the severe cases of gastrointestinal complications experienced elevated symptoms of trauma in comparison with the parents with less severe diagnosis amongst their children. Moreover, the issue of trauma and emotional distress experienced by mothers reaffirmed what was observed in Rwanda by Kidane *et al.* (2022); whose qualitative research finding suggested that among other impacts, emotional impact was prevalent amongst caregivers notably the parents of children diagnosed with gastroschisis. Overall, it can be stated that the majority of these study findings collaborated in the present study especially with regard to the question of traumatic experiences of mothers providing care for their children affected by gastroschisis.

The question of stigmatization and support from the spouse was also at the center stage of the themes identified in the present study. Several mothers reported incidences of stigmatization following diagnosis of their children with gastroschisis which led to experiences of severe isolation. These findings were similar with what was observed by Fisher *et al.* (2022), who took note of the fact that stigmatization can occur amongst parents whose children have been diagnosed with gastroschisis. The study findings also aligned with what was recently observed by Leraas (2023); who made a conclusion that parents of children diagnosed with gastroschisis always face stigmatization in the community. Additionally, the question of reaction of family members was put into consideration in the current study. This can either be a negative or positive reaction. In this regard, support for the mothers whose neonates have been diagnosed with gastroschisis is necessary in order to improve their quality of life. Analysis of the findings reveal that most of the mothers received support from the family members after learning that their neonates had been diagnosed with gastroschisis. The findings were therefore similar with what was observed earlier by Acharya *et al.* (2022) who outlined this with the difference of approved quality line of life of mothers whose children are diagnosed with gastroschisis following discharge from the neonatal intensive care unit (NICU).

Conclusions

The study also concluded that mothers with children with gastroschisis experienced various mental challenges due to inadequate support from close family members. The mothers were not given any warning or information about the condition before their children were born, so they were unprepared to deal with the stress and difficulties related to the diagnosis. Prior knowledge and counseling could have reduced the emotional trauma. It could have also prepared them to handle the situation Positively.

Finally, the research concluded that some of the nurses working did not have any knowledge on gastroschisis. According to the data given by the mothers of neonates, the nurses attending to them didn’t have knowledge on how to handle the condition. According to research, additional beds should be made available for postnatal mothers to ensure comfort during the hospitalization period. Comfortable accommodation would ensure that mothers are relaxed when they are not attending to their neonates therefore reducing emotional trauma.

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