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BARRIERS AND ENABLERS EXPERIENCED BY MOTHERS INVOLVED IN THE NEONATAL INTENSIVE CARE OF THEIR BABIES WITH GASTROSCHISIS

By

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Submitted in fulfilment of the requirements for the degree

MNurs

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DEDICATION

In loving memory of My late Dad, Abram Maesela Masenya, the best Dad I could have ever asked for. Your departure was premature as you passed on while I was still a teenager, yet your teachings remained in me to this day. I am thankful for all that you bestowed on my life.

- My late bosom friend, Isabella Duduzile Banda, your passing left my heart broken with so many unanswered questions. Thank you for always believing in me. I will forever keep you in my heart.
- This work is also dedicated to the many people who inspired me to follow my dream:
- My mom, Botjeetja Francina Masenya for the wisdom she has bestowed on me, for making me believe that I can always achieve anything I want, and that hard work pays off.
- My husband, Tshepang Tlapu Ramosepele for his love and for always believing in me.
- My sibling, Johanna Thakadu ‘Pinky’ Masenya, for her prayers, love, and support at all times.
- My nephew, Keatlegile Thatego Masenya for always believing that I am a star.
- My niece, Mphoentle for always seeing me as an inspiration.
- My kids, Reneilwe Ramosepele and Sbongiseni Bridgette Nzimande.
- My Brother, Stanley Masenya for always believing in me.
- My cousins and friends for their support and words of encouragement.

I am grateful for your love and support. May the Lord God shine His light upon you and bless you always.

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- My editor, Nikki Sutherland for editing my dissertation. Her effort, support, dedication, and meticulous work is highly appreciated.

DECLARATION

Student number: 15250726

I, **Shirley Lina Masenya**, declare that '**Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis'** is my original work and that it has not been submitted before for any degree at any other institution.
All the sources used or quoted have been indicated and acknowledged through complete referencing in the text and the attached reference list.

____________________ ___________

Researcher signature Date

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ABSTRACT

Background

Giving birth to a high-risk or critically ill baby who is admitted to the Neonatal Intensive Care Unit (NICU) for special care, portends maternal distress, anxiety, depression, and feelings of ambivalence and shame. Upon admission of the baby to the NICU, the mother is unprepared, not only to confront the demands of the critical care environment but also to assume her role as a primary caregiver. Evidence points out the importance of parents being present in the NICU at the bedside of their baby or involved in the care of their baby, but the physical NICU environment, policies and rules in the NICU, and bedside manner of staff are some of the factors that mothers faced when taking care for their babies with gastroschisis and admitted to the NICU. These factors that the mothers' experience may become barriers that impact the involvement of the mothers in care activities and may result in the development of maternal stress and affect the long-term developmental outcomes of the babies. Little is known about barriers and enablers experienced by mothers when caring for their babies with gastroschisis in the NICU.

Aim

This study aimed to explore and describe barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

Design

The research design proposed for this study was qualitative, following an explorative and descriptive design.

Methods

Qualitative data were collected through conducting 11 individual, semi-structured face-to-face interviews to explore the experiences of mothers to describe the barriers and enablers they encounter when involved in the neonatal intensive care of their babies with gastroschisis. The population included mothers of babies with gastroschisis admitted to the NICU. Interviews were conducted a few days after the admission of these babies. Convenience sampling, also known as availability sampling, was used to select 11 mothers to participate, as these mothers were readily available as participants for the study. Data were analysed using content analysis as described by Yin (2016:186)

Findings

For barriers, four categories emerged, namely emotional barriers, barriers related to the baby, healthcare system-related barriers, and social 11 barriers. For emotional barriers, three subcategories were identified, while two subcategories for each of the other three categories emerged. Enablers describe three categories and three subcategories each for coping strategies and opportunities to enable mothers. The emotional enablers as a category, have two subcategories.

Recommendations

Recommendations for the healthcare system and to enable the mothers were formulated. The study findings as recommendations provided insight into re-structuring the psychologist or social worker support services available to provide emotional support to the mothers involved in the neonatal intensive care of their babies with gastroschisis. Other recommendations included enablers to enable mothers to bond with and take care of their babies.

Key concepts

Barriers, enablers, gastroschisis, mothers, Neonatal Intensive Care Unit

LIST OF FIGURES

LIST OF TABLES

LIST OF ANNEXURES

Annexure A	Letter of Approval Ethics
Annexure A1	Letter of Approval from Faculty of Health Sciences
Annexure A2	Letter of Approval from Departmental In-House Committee
Annexure B	Declaration of Originality
Annexure C	Interview Guide
Annexure D	Informed Consent Form
Annexure E	Hospital Permissions to conduct research
Annexure F	Declaration for the storage of data
Annexure G	Declaration of Helsinki
Annexure H	Participant 9 Florida – Transcript – Individual Interview
Annexure I	Editor’s Letter

LIST OF ACRONYMS

CEO	Chief Executive Officer.
COVID-19	Notifiable Medical Conditions (NMC) (2020:1) Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the causative virus of coronavirus disease 2019 (COVID-19). The WHO has declared a global pandemic.
NICU	Neonatal Intensive Care Unit.
NHRD	National Health Research Database.
WHO	World Health Organization.

CONTENTS

CONTENTS

CONTENTS

1. ORIENTATION TO THE STUDY

1.1. Introduction and Background

Gastroschisis is not only regarded as one of the congenital abnormalities which occur on a more regular basis in sub-Saharan Africa (Wright, Zani & Ade-Ajayi 2015:1), but the incidence thereof is increasing globally from 1 to 2 in 2010 to 4 to 5 per 10 000 live births in 2020 (Coelho, Silvestre, Figueira, Guimaräes, Castral, et al. 2020:1; Ford, Poenaru, Moulot, Tavener, Bradley, et al. 2016:1262; Wright et al. 2015:1).

Gastroschisis is a full thickness congenital anterior abdominal wall defect (Anyanwu, Ade-Ajayi & Rolle 2020:579; Coelho et al. 2020:1; Wright et al. 2015:1) which is characteristically located to the right of the umbilicus (Anyanwu et al. 2020:579; Coelho et al. 2020:1) and allows herniation of the abdominal viscera to externalise abdominal contents such as the small and large intestines without covering of the hernia sac (Coelho et al. 2020:1; Wright et al. 2015:1).

While the occurrence of gastroschisis is regarded as more regular, the risks associated with fluid shifts and physiological alterations (Anyanwu et al. 2020:579) require emergency interventions for resuscitation and cardiorespiratory support (Wright et al. 2015:1), stabilisation and fluid replacement of the baby (Anyanwu et al. 2020:580). Other interventions during management include decompression of the stomach by the passage of a nasogastric tube and bowel protection (Anyanwu et al. 2020:580; Wright et al. 2015:1). Further management includes reduction of the viscera (Wright et al. 2015:1) and nursing the baby in a controlled thermal environment to prevent heat loss and prevention of further damage to the exposed bowel or mesenteric veins (Anyanwu et al. 2020:580). For these reasons, as well as interventions to return the eviscerated bowel to the abdominal cavity, a baby born with gastroschisis needs to be transferred to the closest healthcare facility and admitted to a NICU for specialised care.

In the healthcare facility where the researcher works, babies born with gastroschisis are admitted directly to the NICU or transferred from peripheral healthcare facilities for admission. It is a requirement that mothers accompany their babies and be present in the NICU to prevent disruption of the bonding process, for fulfilling the care needs of their babies such as feeding, nappy changes, bathing, and to be involved in decision-making and giving consent for surgery. Common stressors the mothers face when in the NICU environment, include aspects such as anxiety and stress about their infants' well-being and progress, loss of their parenting or maternal role to the staff in the NICU followed by poor adjustment to the health of their infants (Williams, Patel, Stausmire, Bridges, Mathis, et al. 2018:1).

Despite the common stressors the mothers are facing, the known importance of bonding and physical closeness between the mother and her baby in the NICU (Flacking, Lehtonen, Thomson, Axelin, Ahlqvist, et al. 2012:1032) and practising of a family-centred care approach are disregarded as the mothers in the setting were admitted in a lodger ward which is near to the NICU. The mothers did not continuously share the bedside with their babies and therefore did not spend much time involved in their care. Parental stress emanating from the NICU environment has the potential to exacerbate the overall stress levels of mothers and is associated with concurrent parental anxiety and depression (Lim, Jayah & Soon 2017:56).

The focus is on the NICU environment, and the stressors in the environment (Williams et al. 2018:2; Musabirema, Brysiewicz & Chipps 2015:1,3), parental experiences of the NICU (Palma, von Wussow, Morales, Cifuentes & Ambiado 2017:335-337; Lilo, Shaw, Corcoran, Storfer-Isser & Horwitz 2016:17-18; Obeidat, Bond & Callister 2009:26017) as well as the needs of mothers with babies in the NICU (Sikorova & Kucova 2012:332-335; Barkin, Wisner, Bromberger, Beach & Wisniewski 2010:1498) and little is known about the barriers and enablers mothers are facing when they take care of their babies in the NICU environment. The study aims to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

1.2. Literature Review

Babies born with gastroschisis are more likely to be premature, of low birth weight or small for gestational age at birth (Coelho et al. 2020:4; Wright et al. 2015:4), which also necessitates admission for management and interventions in the NICU. The NICU environment is a very structured and complex environment which includes the use of several forms of technology, constant alarming sounds and distressing sights of critically ill babies (Palma et al. 2017:333; Musabirema et al. 2015:2; Sikorova & Kucova 2012:330; Hopwood 2010:54; Obeidat et al. 2009:23). The NICU environment has an impact on the physical and emotional closeness between the sick baby and the mother (Flacking et al. 2012:1032). The physical closeness between the mother and her baby in the NICU refers to spatial nearness (closeness) and includes activities such as skin-to-skin contact (Flacking et al. 2012:1032) or holding or touching the baby (Palma et al. 2017:337; Hopwood 2010:54) and feeding the baby (Palma et al. 2017:337). Emotional closeness relates to emotional connectedness to a baby and the experiencing of feelings such as affection, love, warmth and care (Flacking et al. 2012:1032). It is also possible for a mother to be physically present in the NICU her baby’s bedside but become emotionally disconnected from the baby (Flacking et al. 2012:1032).

The environment and care practices in the NICU impact the closeness between the mother and her sick baby, and when separation occurs, whether physical or emotional, it has detrimental effects on both the mother and the baby.

Mothers are at risk of developing maternal anxiety, depression, loss of maternal confidence to be the primary caregiver, feelings of alienation and giving over care responsibilities to staff (Flacking et al. 2012: 1033). Other maternal responses include emotions such as disappointment and ambivalence, fear, shame, guilt and failure to conform to social justice due to the birth of an unhealthy baby (Sikorova & Kucova 2012:330; Obeidat et al. 2009:24). According to Palma et al. (2017:333) the prevalence of mental health and relationship problems between parents increase when a sick baby is admitted in the NICU, while Feeley, Robins, Genest, Stremler, Zelkowitz et al. (2020:2) reviewed that mothers who have babies in the NICU are at risk of developing depression up to a year after the birth of the baby and rates of maternal clinical depression can become as high as 40% in the first three months after birth. The development of similar mental health issues as a result of having a sick baby in the NICU, as stated by Feely et al. (2020:3), is also documented by Williams et al. (2018:1- 2); Lim, Jayah and Soon (2017:56); Del Fabbro and Cain (2016:281) and Flacking et al. (2012:1033). In their discussion of parental perceptions of stress in the NICU, Musabirema et al. (2015:3) drew a correlation between the amount of stress parents experience and language and cultural factors in the NICU as aspects that influence parental behaviour and ability to take care of the sick baby.

Loss in closeness between the mother and her sick baby in the NICU has unfavourable effects on early neurobehavioral development and long-term outcomes of the baby (Flacking et al. 2012:1032-1033), the bonding process and attachment become impaired (Feely et al. 2020:2; Flacking et al. 2012:1033) and may influence emotional programming (Flacking et al. 2012:1033), language development (Feely et al. 2020:2) and infant mental health (Del Fabbro & Cain 2016:281).

Staff who are working in the NICU also found it challenging to facilitate a collaborative relationship with the mother or parents due to the technological environment of the NICU (Musabirema et al. 2015:3) and stress emanating from NICU staff is noted to influence parental stress, parents' long-term relationship with their infants and the ability to take care of their babies (Lim et al. 2017:56).

The literature reflects on stress perceived or experienced by mothers or parents after the admission of their baby to the NICU (Williams et al. 2018:2-3; Lim et al. 2017:56; Palma et al. 2017:333; Obeidat 2009:24), the view of mothers on factors such as the fulfilment of their maternal role, decision making, the sight of their sick infant on life supporting-monitoring devices and their inability to 'help' their babies (Feeley et al. 2020:2; Williams et al. 2018:6; Lim et al. 2017:56-60; Lilo et al. 2016:15-16; Flacking et al. 2012:1033-1034; Sikorova & Kucova 2012:330), but there is a paucity in evidence of barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

1.3. Rationale

Working as a child nurse in the NICU, the researcher observed how frightened the mothers who gave birth to babies with gastroschisis were. These mothers were saddened by the fact that their babies looked different than other babies and were frustrated by the sight of the abdominal contents being visible outside the abdominal wall resulting in difficulty bonding with and caring for their babies. The researcher then noticed that the presence of the abdominal wall defect and lack of maternal knowledge made it difficult for the mothers to fully understand the condition and their maternal role in caring for their babies that influence the relationship between the mother, the nursing and medical staff and the treatment plan for the baby.

This study explored and described the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The results of this study revealed the barriers and enablers experienced by the mothers of gastroschisis babies and recommendations were developed to overcome those barriers experienced by the mothers (view Chapter 3 and Chapter 4).

1.4. Problem Statement

The transition into motherhood is naturally regarded as a period of excitement and has aspects that influence the customary adaptation to the role of motherhood (Heydarpour, Keshavarz & Bakhtiari 2016:138). The early stages of motherhood are regarded as lonely, and require adult interaction and the maternal ability to take care of her own physical and emotional needs (Korukcu, Deliktas & Kukulu 2017:593; Barkin et al. 2010:1494).). Mothers with babies born with gastroschisis occasionally face additional challenges such as premature, low birth weight or small for gestational age baby (Coelho et al. 2020:4; Wright et al. 2015:4), in addition, the mother may be of young age (Skarsgard 2016:346). Admission of a sick baby to the NICU is not only a frightening experience but impedes the early needs of the mother for self-care, good physical appearance, adequate sleep and a healthy baby (Moe, Skisland & Söderhamn 2017:2).

These mothers start their journey into motherhood in the unfamiliar and frightening environment of the NICU (Palma et al. 2017:333; Obeidat et al. 2009:23) and the maternal attachment they developed during pregnancy becomes inhibited.

The unknown prognosis and long-term outcomes associated with a sick baby born with gastroschisis influence the psychological well-being of the mother (Loewenstein 2018:495; Flacking et al.

2012:1033), resulting in stress, anxiety, feelings of guilt and incompetence (Sikorova & Kucova 2012:330; Obeidat et al. 2009:24) and insecure maternal attachment processes developed due to unresolved maternal grief (Twohig, Reulbach, Figuerdo, McCarthy, Mcnicholas, et al. 2016:160).

The researcher observed that the physical environment in which the sick babies were nursed, sometimes made it difficult for the mothers to foster closeness, touch, hold and feed and change the baby’s diaper. The admission of the mothers in the lodger ward with infrequent visits to the sick babies contributed to interruption in physical and emotional closeness between the mother and the baby. It also became evident to the researcher that the staff in the NICU were so focused on their own coping strategies and emotional stress and that cooperative support to the mothers were lacking.

Taking into consideration the above that withheld the mothers with babies with gastroschisis from fully participating in the neonatal intensive care of their sick babies, there was a need to explore and describe the barriers and enablers experienced by these mothers.

1.5. Significance Of The Study

The results of this study benefited the mothers as commendations were developed to assist these mothers to overcome the barriers they experienced in caring for their babies with gastroschisis and being admitted to the NICU. The mothers would be enabled to perform their maternal roles in NICU, such as changing diapers, bathing and feeding their babies without any fears and building a bonding relationship and closeness with their babies. The recommendations also benefited the babies as their mothers would develop a positive attitude and an understanding towards their hospitalisation and treatment. The results of this study would also be beneficial to the hospital with regards to nursing and medical staff as they would be informed of the barriers and enablers (findings of the study) and learn the importance of actively involving mothers in the treatment plans and general care of their sick babies. A strategy for the NICU could be developed and policies may be reviewed (view Chapter 4).

1.5.1. Research Questions

The overall research question formulated for this study was:

What are the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis?

1.5.2. Aim And Objectives

The study aimed to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The following objectives were articulated for this study:

- To explore and describe the barriers experienced faced by mothers involved in the neonatal intensive care of their babies with gastroschisis
- To explore and describe the enablers experienced faced by mothers involved in the neonatal intensive care of their babies with gastroschisis
- To formulate recommendations for mothers involved in the neonatal intensive care of their babies with gastroschisis

1.6. Concept Clarification

The following concepts were defined and will be used consistently throughout the study:

1.6.1. Babies (infants)

A baby is regarded as a newborn or infant younger than 28 days of age (World Health Organization (WHO) 2020:1). This study included babies younger than 28 days, who were born with a gastroschisis defect and admitted to or transferred into the NICU for management. These babies were accompanied by their mothers who were responsible for providing care activities in the neonatal intensive care environment.

1.6.2. Barriers

According to Stevenson and Waite (2011:122), a barrier is an obstacle that hinders or obstructs movement, access, understanding or progress. The researcher believed that certain factors or aspects present in the NICU were causing stress to the mothers and preventing them from becoming involved in the care of their babies, therefore, this study explored and described the barriers experienced by mothers involved in neonatal intensive care of their babies born with gastroschisis (view Chapter 3).

1.6.3. Enablers

Garwood (2011:162) regards an enabler as something or someone that makes it possible for a particular event to happen or be done. In this study, enablers were regarded as aspects or factors that need to be explored and described to assist or facilitate mothers to full participation in taking care of their babies with gastroschisis while in the NICU (view Chapter 3).

1.6.4. Gastroschisis

Skarsgard (2016:363,368) describes gastroschisis as a common, structural birth defect that results in a full-thickness anterior abdominal wall opening through which the abdominal viscera (intestines) extrude without amniotic membrane coverage. The defect normally appears on the right side of the umbilicus, the babies are born slightly preterm and are admitted to the NICU for cooperative management (Skarsgard 2016:363). Babies who were born with gastroschisis admitted to the NICU and accompanied by their mothers were included in this study.

1.6.5. Mothers

According to Stevenson and Waite (2011:961), a mother is a woman in relation to her child, has given birth to the baby and has the responsibility to physical and emotional care for the specific child. In this study, the mothers were the responsible persons who needed to be available at the bedside of their babies with gastroschisis and admitted to the NICU to participate in the neonatal intensive care of their babies. The mothers were invited to participate in this study.

1.6.6. Neonatal Intensive Care

Neonatal intensive care is the therapeutic care provided in the NICU environment that is part of the treatment for critically ill or sick babies (Montanholi, Merighi & de Jesus 2011:302) and refers to normal care activities which can be provided by the mother (Kamphorst, Brouwer, Poslawsky, Ketelaar, Ockhuisen, et al. 2018:3).

Care activities such as taking of the baby’s temperature, diaper changing, feeding, oral and skin care of the baby, assisting with tube feeding, changing of linen, kangaroo care if possible and pumping of breastmilk at the bedside are some of the neonatal intensive care activities the mothers can become involved in (Kamphorst et al. 2018:6). In this study neonatal intensive care referred to the involvement of mothers with babies with gastroschisis in neonatal intensive care and included any care activities that can be done by the mother for her baby.

1.7. Context

This study was conducted in neonatal intensive care units of 3 hospitals, 2 were Academic hospitals in Gauteng province and one was a Provincial hospital in Gauteng province. The 2 NICUs in academic hospitals in Gauteng province admit critically sick babies from the neighbouring district hospitals and peripheral hospitals from other provinces, such as Northwest and Limpopo. The average number of babies admitted with gastroschisis over a six-month period (February 2020-August 2020) in the initial hospital was 11

The NICUs in one of the hospitals in Gauteng and the one in Limpopo made provision for the mothers to be admitted in the adjacent wards as lodgers to enable their involvement in the neonatal intensive care of their babies. However, the other NICU in Gauteng only admitted the mothers who were breastfeeding in to their lodger ward, this was as due to COVID-19 restrictions

The context of the study was extended to these other hospitals because the researcher experienced a lack of participants in the identified Gauteng Province Hospital due to COVID-19- associated changes in the transferral and admission process of babies born with gastroschisis (view Annexure D3).

The similarities between the three NICUs is that, they all have the following cubicles: 1) Main Intensive care unit for newly admitted babies who need emergency care and life support; 2) the High care cubicle which is for babies who are recovering on either room air, nasal prongs oxygen and or on noninvasive ventilation support; 3) the Surgical cubicle allocated for babies who require emergency care and surgical interventions; 4) the Nursery/General cubicle which is also referred to as the discharge area for babies who are ready to go home and lastly, 5) The isolation cubicle which is reserved for babies with infections. The difference between the hospital was the bed occupancy, one hospital in Gauteng Province has the bed occupancy of 55 babies, and the one in Limpopo has the occupancy of 52 bed, whereas the other one in Gauteng has bed occupancy of 37.

1.8. Philosophical Assumptions

Tracy (2020:49) suggests that philosophical assumptions are paradigms that are used as preferred ways of understanding reality, building knowledge, and gathering information about the world. Paradigms are collections of discourses that make up the philosophical assumptions that ground one’s point of view and can differ based on ontology (the nature of reality) and epistemology (the nature of knowledge) (Tracy 2020:49).

In this study, a constructivist paradigm was followed whereby, the production of reconstructed understanding provided through the use of narratives and phrases of the participants to describe barriers and enablers experienced when involved in the neonatal intensive care of their babies with gastroschisis were applied (view Chapter 3).

1.8.1. Ontological Assumptions

Ontology is a patterned set of assumptions about reality (Brink, van Der Walt & van Rensburg 2018:19). To find out the nature of reality, the researcher used relativism to understand the reality about the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The researcher interviewed the mothers (participants) and used phrases and words of the participants to describe the barriers and enablers experienced by them when taking care of their babies. This enabled an understanding of the reality (the barriers and enablers faced) according to the point of view of the mothers.

1.8.2. Epistemological Assumptions

Epistemology refers to the knowledge of reality (Brink et al. 2018:19). Because epistemological assumptions assume that knowledge is created, the researcher will interpret and analyse the experiences as explained by the participants (mothers) in this study to describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The findings resulted in knowledge about the barriers and enablers faced by these mothers (view Chapter 3).

1.8.3. Methodological Assumptions

Methodological assumptions relate to the way or manner in which a study will be conducted, including aspects such as the research design, data collection and data analysis (Brink et al. 2018:19; Offredy & Vickers 2010:24) and occur in a natural setting while using inductive reasoning (Offredy & Vickers 2010:24). The researcher used a qualitative design and applied constructivism to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. Constructivism is perceived by Walliman (2011:22) as a world experienced through perceptions, experiences, values and beliefs where the researcher becomes part of this world and uses inductive methods to explore and give meanings to the personal experiences of the participants. Methodological assumptions will be discussed in the sections under qualitative research design (In-depth discussion in Chapter 2).

1.9. Delineation

This study was conducted in the NICU of a selected hospital in Gauteng province, including two peripheral hospitals. The extension of the context had no influence on the findings and recommendations of the study as the study included mothers who had babies with gastroschisis, were admitted to the NICU and were involved in the neonatal intensive care of their babies.

1.10. Qualitative Research Design

According to Brink et al. (2018:104), qualitative research refers to a broad range of research designs and methods used to study a phenomenon. This type of design was used by the researcher to explore the meaning or describe and provide an in-depth understanding of human experiences, based on the view of Brink et al. (2018:103). Qualitative studies are conducted in natural settings in an environment as it occurs and not manipulated (Offredy & Vickers 2010:24).

The research design for this study was a qualitative explorative and descriptive design. The purpose of employing this type of design was to explore and describe barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis (view Chapter 2).

1.11. Data Collection

Data serve as a foundation for a research study. In qualitative research, the relevant data may come from four data collection methods: interviewing, observing, collecting and examining (materials), and feeling (Yin 2016:137), while Brink et al. (2018:142) believe that interviews produce in-depth information regarding the interviewees' beliefs, experiences and attitudes. The researcher approached the mothers to explain the study and asked for consent for participation (view Annexure D).

Data were collected using individual, semi-structured face-to-face interviews with mothers involved in the neonatal intensive care of their babies with gastroschisis (view Annexure B: Interview guide). This method enabled the participants to respond freely to the questions and probing that described and explained the barriers and enablers they experienced when they were involved in the neonatal intensive care of their babies with gastroschisis for rich descriptive data (view Chapters 2 and 3).

1.11.1. Pilot Interview

According to Brink et al. (2018:161), a pilot study sometimes referred to as a 'preliminary study,' is a small-scale study conducted before the main study on a limited number of participants. The purpose of a pilot study is to investigate the feasibility of the proposed method of data collection and to detect possible flaws in the methodology of the proposed study Although a pilot study is of less concern in qualitative data collection because data analysis is ongoing (Offredy & Vickers 2010:85), a pilot interview was held prior to the data collection in the main study with two mothers who met the inclusion criteria to ensure that the questions asked by the researcher resulted in data that answered the research question. No changes were made in the interview guide post pilot study, therefore data obtained in the pilot study was included in the main study (view Chapter 2).

1.12. Data Reorganisation

Data reorganisation is the process of managing and organising qualitative data. This step allows the researcher to become immersed in the data (Brink et al. 2018:180). The researcher used the reordered interviews, the field notes and reflection during collection for data to be organised.

The researcher ensured the trustworthiness of the data by ensuring that the interviews were transcribed and proofed against the recorded interview (Brink et al. 2018:180) (view Chapter 2).

1.13. Data Analysis

Data analysis is defined as several techniques used to display data and aimed at answering the research questions (Brink et al. 2018:165). Data analysis requires careful planning, which entails categorising, ordering and summarising the data to describe information in meaningful terms (Brink et al. 2018:165). Data were analysed using a hands-on process, during which the researcher became deeply immersed in the data as perceived by Brink et al. (2018:180). This data analysis process was done to ensure the accuracy of the collected data. The researcher reviewed, read and re-read all collected data for analysis. All transcripts were read and re-read to get a sense, insight and understanding of the barriers and enablers experienced by mothers (participants) involved in the neonatal intensive care of their babies with gastroschisis (view Chapter 2).

According to Yin (2016:186), the analysis of qualitative data usually involves five phases. A short description of the phases is provided below as discussion occurs in Chapter 2.

The first analytic phase: **Compiling** data into a formal database, through careful and methodical organising of the original data. The researcher formally arranged all the notes gathered from data collection in some useful order. The completed compilation might be considered a database (Yin 2016:186).

The second phase, which is the breaking down of the compiled data into smaller fragments or pieces, is considered a **Disassembling** procedure (Yin 2016:186). In the disassembling procedure, the researcher repeated the disassembling procedure many times as part of a trial-and-error process of testing and refining labels, accounting for a two-way arrow between these first two phases. The outcome of the disassembling phase formulated substantive themes, based on combinations of disassembled items, to reorganise the fragments or pieces into different groupings and sequences obtained from the original notes. Disassembling the data in a database involved a formal coding procedure but does not need to (View Annexure G3)

The third phase, known as **Reassembling**, is less mechanical and benefits from the researcher's insightfulness in seeing emerging patterns. The researcher's rearrangements and recombination in reassembling were facilitated by depicting the data by arraying it in lists and other tabular forms (Yin 2016:187).

The fourth phase the researcher used was reassembling the material to create a new narrative, with accompanying themes and sub-themes. This phase is considered as **Interpreting** the reassembled data. The initial interpretations may lead to the desire to recompile the database in an innovative way, or to disassemble or reassemble the data differently until the data answers the aim and research question of the study (Yin 2016:187).

The fifth and final phase was **Concluding,** and with concluding the researcher concluded the data. Such conclusions were related to the interpretation in the fourth phase and through it to all the other phases of the cycle (Yin 2016:187).

1.14. Data Interpretation

Data interpretation relates to the original problem and research question (Brink et al. 2018:180). The findings of the study should be related to pre-existing literature, concepts, theories and research evidence to bring along a dialogue between the conclusions and the literature for the researcher to determine whether the results have practical significance (Brink et al. 2018:80). The researcher interpreted the data and described the narratives to give meaning to the outcomes yet relating the meaning to the original problem. (View Chapter 3)

1.15. Trustworthiness

Gray et al. (2019:593) define trustworthiness in a qualitative study as the extent to which the interrelated characteristics of authenticity, credibility, transferability, dependability, and confirmability of the study findings are evident in the research report. The researcher followed the preceding strategies to ensure trustworthiness in the study. A summary follows as an in-depth application in Chapter 2.

1.15.1. Authenticity

According to Brink et al. (2018:111), authenticity can be established by rich context and meaningful descriptions. To ensure authenticity in the study, the researcher explored the meaning of the different views of the participants to understand what the participants consider as barriers and enablers when they were involved in the neonatal intensive care of their babies with gastroschisis (view Chapter 2:Section. 2.7.5.)

1.15.2. Confirmability

Refers to the guarantee that the findings, conclusions and recommendations are supported by the data and that there is an internal agreement between the researcher’s interpretation and actual evidence (Brink et al. 2018:111). This was also accomplished by incorporating an audit trail of detailed recordings of the interviews, transcripts, field notes and the process of interviews to ensure that the findings can be followed to guarantee confirmability (view Chapter 2:Section 2.7.3).

1.15.3. Credibility

Credibility refers to confidence in the truth of the data and the interpretation thereof. The investigation in a study must be done in such a way that the findings are credible or believable (Brink et al. 2018:158).

To ensure credibility, the researcher took notes and made use of audio recordings during interviews to explore the participants' views, feelings or perceptions regarding barriers and enablers they experienced when they were involved in the neonatal intensive care of their babies born with gastroschisis. Other methods the researcher used to ensure credibility were to allow time for the participants to narrate their stories and give in-depth descriptions of what they regard as the barriers and enablers they experienced when they were involved in the neonatal intensive care of their babies with gastroschisis (view Chapter 2: Section 2.7.1 and Annexure C).

1.15.4. Dependability

This criterion refers to the documentation of steps taken and decisions made during qualitative analysis (Gray et al. 2019:569) to ensure the stability of data over time. The researcher kept detailed information regarding methodological, theoretical, and field notes to perform a dependable trial (view Chapter 2:Section 2.7.2).

1.15.5. Transferability

According to Gray et al. (2019:593), transferability refers to the extent to which findings from data can be transferred and made applicable to other settings with conserving the meaning. This was accomplished through thick and detailed discussions of the findings (view Chapter 2:Section 2.7.4).

1.16. Ethical Considerations

The researcher conducted the research in an ethical manner from the conceptualisation and planning phases, through the implementation phase, to the dissemination phase (Brink, van Der Walt & van Rensburg 2015:32). There researcher had the right to search for the truth in the most rigorous way, but never at the expense of the right of the individual and communities (Brink 2015:32). The researcher obtained informed concern which meant that the ethical principles of voluntary participation and protecting the participants from harm were formalised in the concept of informed consent (view Annexure D) and no participant was coerced to take part (view Chapter 2). The study only commenced after permission of the University of Pretoria Research Ethics Committee, the CEO of the selected hospitals in both Gauteng and Limpopo Department of Health was granted (view Annexures E). Ethical principles that were adhered to:

1.16.1. Respect For Human Dignity

All the participants were invited to participate, given a chance to accept or withdraw at any time they requested or refused to give information they did not feel like sharing, as stated by Polit and Beck (2017:140). When emotional discomfort developed, the participant would be referred to a social worker or psychologist who was available for consultation (view Chapter 2).

1.16.2. Justice

The information would not be published in a format that may lead to the identification of any participant (Polit & Beck 2017:141) and participants were reassured that any information discussed and obtained from the individual interviews would be kept confidential and what was discussed in the interview session would remain confidential. The participants were requested not to share any information with other mothers (people) outside the individual group participants. This principle also refers to fair treatment and respect for the privacy of the participants.

1.16.3. Beneficence

To adhere to this principle, the researcher needs to secure the participant’s well-being. The participant has a right to be protected from discomfort and harm – whether physical, psychological, emotional, economic, social or legal. If a research problem involves a potentially harmful intervention, it may have to be abandoned or at least restarted to ensure it meets ethical requirements (Brink et al. 2018:29) (View Chapter 2).

1.17. Layout Of The Dissertation

A particular layout for this study was followed. The next diagram summarises the layout.

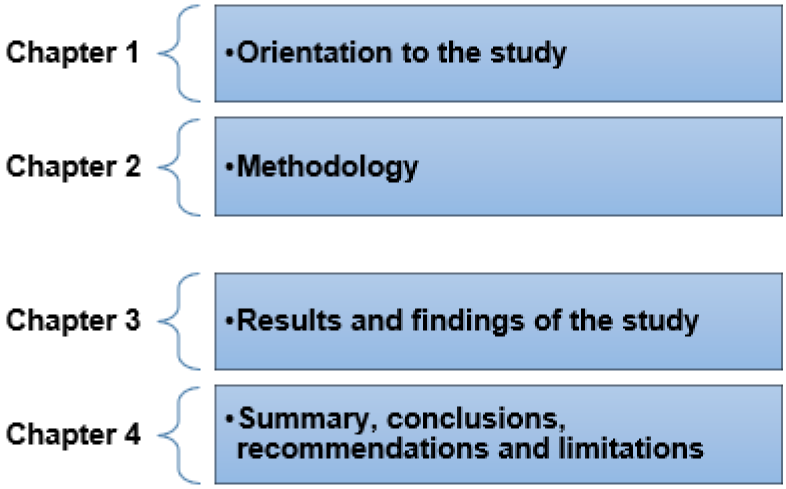

Figure 1.1: Layout of the Study.

1.18. Summary

In this chapter, an orientation was provided, which included the introduction and background as well as the rationale for the study and its significance. An overview of the problem statement, aim, objective, research design and method was discussed, and ethical considerations were observed. The next chapter focuses on an in-depth discussion of the research methodology.

2. METHODOLOGY

2.1. Introduction

Chapter 1 provided the orientation and overview of the study. Chapter 2 discusses the methodology followed during data collection to explore and describe the barriers and enablers experienced by mothers when taking care of their babies who were born with gastroschisis and admitted to the NICU.

This chapter includes a discussion on the qualitative design, sampling and sampling plan, population, data collection, data analysis and application of methods that ensured trustworthiness in the study. This methodological approach was used to answer the following research question:

What are the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis?

2.2. Research Methodology

Research methodology informs the reader of how the investigation was carried out, that is what the researcher did to solve the research problem or to answer the research question (Brink et al 2018:187) According to Offredy and Vickers (2010:65) Methodology refers to the process and steps the researcher will use to conduct the study and includes the selection of the population, sampling approach, data collection, data analysis and reorganising and trustworthiness of the data. Following is a short orientation to the research methods, and an in-depth discussion is provided in Chapter 2. methodology also refers to the process and steps used by the researcher to conduct a study (Offredy & Vickers 2010:65). In this study, a qualitative research design was followed. According to Brink et al. (2018:104), qualitative methodology is applied when little is known about a phenomenon, or when the nature, context and boundaries of a phenomenon are poorly understood or defined.

2.3. Qualitative Research Design

Qualitative research is defined by Gray, Grove and Sutherland (2017:143) as research that allows researchers to explore the depth, richness, and complexity inherent in the lives of human beings, whereas according Gray and Grove (2019:89), qualitative research is a systemic approach used to describe experiences and situations from the perspective of persons in the situation. The researcher perceived a qualitative design as appropriate to find meaning in the words and described the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis to make available a deeper understanding of their experiences (view Chapter 3).

According to Polit and Beck (2018:210), a qualitative research design spells out the strategies that the researcher adopts to answer their questions, while Brink et al. (2018:104) refer to qualitative designs as a broad range of methods used to study phenomena. In qualitative research, the study design often evolves during the project (Polit & Beck 2018:271).

In this study, the qualitative design was emerging which contributed to the fact that the researcher formulated decisions based on the discovered information that was collected from the participants (view Chapter 3 and Chapter 4).

Research designs are further regarded as the plan that outlines and guides a study (Gray & Grove 2019:588). Following the plan provides maximum control over factors that could interfere with the validity of the findings and guides the planning and implementation of a study in a way that is most likely to achieve the intended aim of the study. For a discussion on the steps that guided data collection in this study, view Sections 2.4, 2.5 and 2.6.

An exploratory and descriptive qualitative research design was followed (view Chapter 1: Section 12). The research was conducted in a real-life situation, where the focus was on collecting data from mothers regarding what they experienced as barriers and enablers when involved in the neonatal intensive care of their babies with gastroschisis. The researcher regarded this approach as useful as the motivation of the research was not to generalise the findings but to understand in context the participants' experiences with the barriers and enablers when involved in the neonatal intensive care of their babies with gastroschisis. In this study, the researcher invited mothers of babies with gastroschisis and admitted to the NICU for participation and to allow the researcher to explore and describe the barriers which the mothers experienced when they were caring for their babies as they were present at the bedsides and had become part of neonatal intensive care. The mothers were regarded as having specific knowledge of the barriers and enablers they were facing, and by exploring the depth of barriers and enablers they had experienced, a rich description gave the researcher an understanding and provided insight thereof (view Chapter 3).

2.3.1. Exploratory And Descriptive Design

In this study, the researcher was concerned about the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. In this study, an exploratory and descriptive qualitative design was followed.

2.3.1.1. Exploratory Design

An exploratory research design refers to a design that is used to increase knowledge in the field of a study and is not intended for generalisation (Gray et al. 2017:1289). The researcher did not know of the barriers and enablers for mothers involved in the intensive care of their babies with gastroschisis. The researcher used an exploratory design to explore data and information about the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

The use of this design enabled the researcher to ask open-ended questions followed by probing ones for a detailed exploratory response of the participants' responses to gain insight into barriers and enablers experienced by mothers (view Chapter 3)

2.3.1.2. Descriptive Design

A descriptive design provides an accurate portrayal of the character of a person or a group in a real-life situation (Gray & Grove 2019:258). Where there is a discussion or description of their opinions about health care or the level of care in a particular area (Offredy & Vickers 2010:48). A descriptive design was used in this study. The researcher conducted face-to-face individual interviews with mothers of babies born with gastroschisis and admitted to the NICU to describe the barriers and enablers they experienced when taking care of their babies in the NICU. In this study, the participants responded to the interview questions by giving their experiences as narrative responses, their responses assisted the researcher in understanding the barriers and enablers they faced from their perspective. (View Chapter 3).

Limited information and evidence were available about barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The exploratory and descriptive design assisted the researcher to describe barriers and enablers as the mothers experienced them. The researcher was also enabled to ask and find out from the mothers what could be done to improve involvement in neonatal intensive care of their babies with gastroschisis. Data were described as recommendations (view Chapter 4).

2.4 Population

Brink et al. (2018:116) refer to the population as the entire group of persons or objects that is of interest to the researcher and meet the criteria they are interested in studying. On the other hand Polit and Beck. (2017:365) defined a population as the entire group of cases in which a researcher is interested, and according to Polit and Beck (2018:719), who are available for a particular study.

The participants in this study consisted of mothers involved in intensive care of their babies with gastroschisis. The participants were interviewed two days after the admission of their babies in the

NICU because they needed to familiarise themselves with the new environment and the routine of the NICU and became involved in the care. The participants included were 11 biological mothers of babies born with gastroschisis (view Chapter 3).

Brink et al. (2018:116) state that the population is the entire group of persons or objects that is of interest to the researcher, and which meet the inclusion criteria of the study. The population identified for this study was the mothers involved in the neonatal intensive care of their babies with gastroschisis.

2.4.1 Sampling And Sampling Plan

According to Brink et al. (2018:132), sampling refers to the researcher's process of selecting the sample from a population to obtain information regarding a phenomenon in a way that represents the population of interest. Brink et al. (2018: 117) further defines sample as a part or fraction of a whole or a subset of a larger set selected by the researcher. It consists of a selected group of the elements or units of analysis from a defined population (Brink et al. 2018:117), while sampling is defined by Gray et al. (2017:1324) as selected groups of people, events, or other elements with the purpose to conduct a study. Polit and Beck (2017:386) define sampling for a study as the process of selecting a portion of the population, where the population is regarded as the entire cumulative number of cases.

In this study, the researcher selected mothers of babies born with gastroschisis admitted in the NICU and involved in neonatal intensive care to explore and describe the barriers and enablers they experience. The researcher used convenience sampling, which is also referred to as 'accidental' or 'availability sampling,' and it involves the choice of readily available participants (Brink et al. 2018:125).

Convenience sampling is a type of nonprobability sampling, and according to LoBiondo-Wood and Haber (2018:217), researchers should take care when using this approach to sampling as the sample can be less representative and sampling is less generalisable. The researcher took care to overcome these restrictions through the careful selection of the population by using inclusion and exclusion criteria (view Section 2.4.1.1) and a large enough sample size. Mothers of babies with gastroschisis who were available in the NICU during the period of data collection, were invited to participate and those that had already been discharged were located at their homes for data collection, this came as a result of lack of participants as a result of COVID-19 restrictions, (view Chapter 3). The participants were interviewed two days after admission of the babies in the NICU because they needed time to settle in and familiarise themselves with the new environment and the routine in the NICU. Included were all biological mothers of babies with gastroschisis, aged 18 years and older and speaking English. Exclusion criteria will be mothers who gave birth to babies with gastroschisis but were not reachable or mothers who gave birth to babies with any other abdominal birth defects than gastroschisis. In terms of the number of participants that will be selected, Offredy and Vickers (2010:140) reflect that in qualitative research, the quality of information that is collected will indicate the sample size; this is regarded as saturation. Data saturation occurred when the researcher is no longer ‘hearing ‘ or ‘seeing ‘ new information from the participants, or no additional data can be obtained (Offredy & Vickers 2010:141). The researcher conducted 11 face-to-face interviews (view Chapter 2).

The term ‘participants’ was used in this study to describe the sample selected and used to collect data and describe the findings to meet the objectives and answer the research question (view Chapter 1) (Polit & Beck 2018:257). The sample in this study included 11 mothers who were involved in the neonatal intensive care of their babies with gastroschisis. The initial sample for this study included 11 mothers involved in the intensive nursing care of their babies with gastroschisis. However, the researcher faced challenges regarding the low number of participants for the study. The low number of participants resulted from one of the peripheral hospitals as mentioned under the context for this study, who no longer referred their patients to the chosen Academic hospital in Gauteng Province due to COVID-19 restrictions.

The researcher received approval from the hospital in Gauteng province to commence with data collection, however the researcher was only able to commence with data collection two months post receipt of approval because there was no admission of patients with gastroschisis. This prompted the researcher to go through the records of the gastroschisis admission book in the NICU to try and locate the discharged mothers with the permission of the Supervisor. Two mothers were interviewed at their homes on different dates. The researcher interviewed five participants in the hospital in Gauteng province and then six months passed without new admissions of babies with gastroschisis. The researcher had not reached data saturation and used the option of expanding the study to different Academic Hospitals in Gauteng province and another Hospital in Limpopo Province (view Annexures E).

In application, the advantages of convenient sampling include the following, according to LoBiondo-Wood and Haber (2018:217):

- The sampling method used the most readily accessible participants. This study included the mothers involved in the neonatal intensive care of their babies born with gastroschisis; this implied that the mothers were available at the bedside of their babies and accessible to approach and invite participation.
- It is easier to obtain participants while still keeping in mind that a sufficient number of participants will be required for data saturation to ensue (view Section 2.5).

In qualitative studies, no fixed rules occur that demarcate sample size. The sample size varies and is based on the type of information required and the guiding principle-data saturation (LoBiondo-Wood and Haber (2018:215-216). In this study, the sample size included 11 participants and no participants were excluded.

2.4.1.1. Inclusion And Exclusion Criteria

Inclusion criteria, according to Polit and Beck (2018:274), specify the characteristics of the population the researcher wants to include during data collection. The following were the inclusion criteria:

- Mothers who were 18 years and older and involved in the neonatal intensive care of their babies with gastroschisis.
- Participants who were the biological mothers and involved in the neonatal intensive care of their babies with gastroschisis.
- Mothers who spoke English.
- Mothers who agreed to participate voluntarily in the individual face-to-face interviews.

Polit and Beck (2018:727) regarded exclusion criteria as those characteristics that the sample does not have and, therefore, will not be included as a participant. The following were identified as exclusion criteria:

- Mothers who did not meet the inclusion criteria.
- Mothers involved in the neonatal intensive care of their babies with any abdominal or other

2.4.2. Gaining Access

According to Polit and Beck (2018:729), gaining access is the process the researcher engages in to enter the research site through the cooperation of key gatekeepers in the research site. In this study, the researcher gained access from the following gatekeepers:

- Ethics permission from the University of Pretoria, Faculty of Health Sciences Research Ethics Committee (view recent Ethics approval certificate: Annexure A1).
- Department of Health Research Ethics Committee of Gauteng Province (view attached Annexure A)
- Chief Executive Officer of Dr George Mukhari Academic Hospital (view Annexure E).
- Chief Executive Officer of Mankweng Hospital. Limpopo Provincial Government (view Annexures E).
- Chief Executive Officer of Steve Biko Academic Hospital (view Annexure E)

Due to the COVID-19 pandemic, the researcher was unable to continue with the process of data collection at the hospital mentioned in the proposal. The researcher sought approval from the National Health Research Database (NHRD) to extend her study to another hospital in a different province to continue with the collection of data. The researcher was advised by an NHRD representative to discuss the matter with her supervisors first before she could go ahead with seeking approval from a different province. The supervisors allowed the researcher to seek approval from Limpopo province for the continuation of data collection. The researcher sought approval from Limpopo province and approval was granted. The researcher further made arrangements to access a Hospital in Limpopo Province for the continuation of data collection, She communicated telephonically with the office of research at that hospital in Limpopo.

In the application letters, the researcher explained the aim and objectives, benefits, and the duration of the study. The researcher emphasized ethical principles and that the study and data collection would not interfere with routine healthcare services, and patient care and healthcare delivery would continue without interruption. The researcher was familiar with the sites and the workplace culture of the settings as well as the fact that the majority of mothers (participants) were English-speaking. This detail enhanced the trustworthiness of the data during the data-collection process.

The researcher started with the gaining access process after receiving approval letters from the different gatekeepers (view Annexures D3)

2.4.3. Recruitment Of Study Participants

Recruitment, according to LoBiondo-Wood and Haber (2018:93), refers to the places or settings where the participants for a study will be selected to collect data. In qualitative studies, the settings are referred to as naturalistic settings.

The NICU was the naturalistic setting where the participants were recruited for participation in this study. The researcher used a face-to-face recruitment process by visiting the NICU of the respective hospital. The researcher used the inclusion criteria to select participants, where she verbally explained the study separately to each participant. The researcher ensured by following this step that recruitment was confidential and that questions regarding participation were answered immediately.

Before the researcher commenced the process of data collection, she formally made an appointment to visit the Unit Manager and child nurse specialists in NICU. She also submitted the approved proposal, Ethics permission letters and approval from the Hospital Chief Executive Officer (CEO) to the Assistant

Director of Nursing for Paediatrics. The researcher discussed her proposal with the Unit Manager and child nurse specialists in detail and requested the possibility of being informed should a baby with gastroschisis be admitted to the NICU. When babies were referred from peripheral hospitals for admission, the researcher followed up twice daily until the mothers of the baby were present and started to become involved in the neonatal intensive care of the baby. Several babies were admitted before the mothers arrived at the hospital due to the need for immediate medical attention.

During recruitment, the researcher asked the participants to sign the participation information leaflet after a verbal agreement to voluntary participation.

2.4. Data Collection

Data collection describes the process of generating data for a study (Gray & Grove 2019:361). In this qualitative study, the researcher explored and described the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The words and narratives the participants used to describe their experiences regarding the barriers and enablers were important and decisions about exploring information evolved during data collection to provide in-depth information.

In this study, the researcher used individual semi-structured face-to-face interviews as a method of data collection. Brink et al. (2018:143) suggest that in semi-structured interviews, the researcher typically asks a specified number of focused questions, but can also pose additional ones, depending on the answer and the need to probe for deeper meaning (view Chapter 3). When the questions for the semi-structured interviews were compiled, the researcher took care to ensure that there was a balance between the focused questions about the condition of the baby, the information the participants received and the issues that led to an in-depth discussion (view Annexure C) The questions were compiled to incorporate the aim and objectives of the study (view Chapter 1). Mothers of babies with gastroschisis who were available in the NICU during the period of data collection, were invited to participate and those that had already been discharged were located at their homes for data collection, this came as a result of lack of participants due to COVID-19 restrictions, (view Chapter 3).

During gaining access and recruitment (view Sections 2.4.2 and 2.4.3), the researcher first sought consent from the participants to participate in data collection using individual face-to-face and semi- structured interviews (view Annexure B). The purpose of the study was explained to the participants in a language they understood, while data collection occurred in English. The researcher was responsible for collecting the data and keeping field notes where appropriate (view Section 2.5.6).

The following sections discuss individual face-to-face semi-structured interviews and the role of the researcher during data collection.

2.5. Individual Face-To-Face Semi-Structured Interviews

This study aimed to explore and describe barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. Individual face-to-face semi-structured interviews were used to generate data.

2.5.1. Development of the semi-structure questions

Semi-structured interviews are based on a set of questions, which is captured on an interview guide (Flick 2020:231). The researcher developed the interview guide with semi-structured questions (view Annexure B) to guide the interview. Semi-structured questions aimed to assist the researcher to explore and describe barriers and enablers experienced by mothers when involved in the neonatal intensive care of their babies with gastroschisis. Semi-structured questions provided the researcher with the opportunity to ensure trustworthiness during data collection. The interview guide with the questions was used during the interviews and the same questions were asked to all the participants.

The researcher phrased the questions in such a way that dialogue between the participants and the researcher was initiated, and the participants responded as spontaneously and comprehensively as they wished, without limiting the time for their responses. The researcher also used probing techniques to further explore answers in detail (view Annexure B). No time limit was placed on the duration of the individual interviews to allow freedom for the participants to answer the questions. The average time it took the researcher to conduct the individual face-to-face interviews was between 17 and 40 minutes. The researcher concluded the session when probing did not provide new information or the participant indicated that she had shared all the information regarding the barriers and enablers as she experienced them.

2.5.2. Advantages of face-to-face interviews

The following section focused on the advantages of face-to-face interviews according to Polit and Beck (2018:275-276) and applied to this study. Some of these advantages were used to ensure trustworthiness and ethical considerations.

2.5.2.1. Response Rate

The response rate to face-to-face interviews is high as participants are likely to talk to the researcher. In this study, the researcher used convenient sampling and selected a group of participants in similar situations. The participants recruited all agreed to participate, and the researcher experienced an eagerness among the participants to talk and share their experiences.

As the interviews were face-to-face, there was no requirement for the participants to write or complete any information, thus, participants who were illiterate were also included in the study. Participation was high as the researcher was able to schedule interview times according to a time slot that was suggested by the participants.

2.5.2.2. Confidentiality And Trust

Individual face-to-face interviews provided the participants with privacy to share information about the barriers and enablers they experienced when they were involved in the neonatal intensive care of their babies. Individual face-to-face interviews ensured that a trustful relationship during data collection developed as the researcher spent time with the participants on an individual and personal level and did not rush the sessions.

2.5.2.3. Clarity And Sensitivity Of The Questions

Individual face-to-face interviews enabled the researcher to clarify the questions and use probing when she observed that answers were unclear or misunderstood. The researcher was able to rephrase questions in a sensitive manner that was considerate of the participants' circumstances.

2.5.2.4. Depth Of Questioning

Face-to-face interviews in this study allowed the researcher to build a relationship with the participants to ensure probing and in-depth questioning, without threatening the ability of the participants to give information. The conduction of the interviews was approached from more neutral aspects, and the researcher only probed or looked for in-depth information when she observed that the participants were comfortable sharing more information.

2.5.2.5. Order Of Questions

The questions were ordered in a specific format on the interview guide (view Annexure B). The interviews started with a question that acted as an ice-breaker to ensure that the participants were comfortable.

Then the researcher asked questions about the barriers, followed by the enablers. The last probing question focused on the information that was transcribed as recommendations (view Chapter 4). This approach ensured that all the same questions were posed to each participant.

2.5.2.6. Supplementary Data

Careful observation and keeping field notes provided additional information for the researcher to develop a deeper understanding and insight into the barriers and enablers experienced by the participants when involved in the neonatal intensive care of their babies with gastroschisis.

2.5.3. Disadvantages of face-to-face interviews

The following section acknowledged some of the disadvantages of individual face-to-face interviews.

2.5.3.1. Gaining Trust

In individual face-to-face interviews, it might be a constraint for the researcher to gain the participants' trust (Polit and Beck 2018:507). In this study, the researcher overcomes this disadvantage by visiting the mothers first to explain the study. She sets dates and arranges appropriate times two days later with the mothers. The day before the appointments, she contacts the mothers again to confirm. On the day of the interviews, the researcher dressed professionally as a registered nurse and professionally conducted the interviews.

2.5.3.2. Time And Pace Of Interviews

Polit and Beck (2018:508) warn that individual face-to-face interviews can be timeous as the sessions cannot be rushed. The duration of interviews in this study took between 17 and 40 minutes, and the researcher could only complete one interview per appointment. Babies born with gastroschisis are not a common neonatal condition and it resulted that the researcher had to wait for a baby to be admitted to one of the hospitals before data collection could be planned.

2.5.3.3. Emotional Involvement

Due to the nature of the information and the involvement with the participants, the researcher had to take steps to over-involvement during data collection. The researcher did not express surprise, approval or disapproval of any answers and did not articulate any standpoint or personal view. Although the researcher felt emotionally drained after the interviews, she kept objective field notes and ensured that the data transcription was unbiased according to the voice-recorded interviews. Reflexivity assisted the researcher to stay aware of herself in her role as a researcher and remain neutral. The researcher kept reflective notes about her personal experience during data collection (view Chapter 4).

2.5.4. Pilot Interview Or Pilot Study

A pilot study is viewed by Polit and Beck (2018:624) as a data collection on small scale, conducted before the main study. The aim of a pilot study is not only to confirm the method of data collection, but in this study, the researcher tested the questions and probing questions for clarity, the duration of the interviews, the willingness of the participants to share information and her ability to conduct the interviews.

The researcher conducted two pilot interviews on these dates: (20th and 22nd August 2021) by obtaining information from participants who met the inclusion criteria and voluntarily participated. Data were transcribed and after discussion with the supervisors, included in the study.

The researcher did not make use of a fieldworker to take notes while she conducted the interviews. The researcher realised during the two pilot interviews she conducted that she would be able to listen to the participants, maintain eye contact, ask probing questions and keep additional notes, as the interviews are not hurried and individual in approach. Consent was requested from each participant to voice- record the interviews to ensure the trustworthiness of collected data and all the participants agreed and signed consent to voice recording.

It was concluded that the question and probing questions were suitable to obtain in-depth data and the researcher would be able to take field notes during data collection.

The following table provides a summary of the data collection process in this study.

Table 2.1: Number of interviews, the dates and duration of the interview and setting.

Number of interview	Date	Duration	Setting
1-Pilot interview and included	20 August 2021	17 Minutes	Hospital 1
2-Pilot interview and included	22 August 2021	25 Minutes	Hospital 1 (Interview done at the home the participant)
3	01 September 2021	31 Minutes	Hospital 1 (Interview done at the home the participant)
4	08 September 2021	40 Minutes	Hospital 1
5	11 November 2021	28 Minutes	Hospital 1
6	04 January 2022	31 Minutes	Hospital 1

Table 2.1: Number of interviews, the dates and duration of the interview and setting (continue).

Number of interview	Date	Duration	Setting
7	17 February 2022	30 Minutes	Hospital 2
8	17 February 2022	37 Minutes	Hospital 2
9	21 March 2022	31 Minutes	Hospital 3
10	23 March 2022	27 Minutes	Hospital 3
11	25 March 2022	30 Minutes	Hospital 1

2.5.5. Preparing For The Individual Face-To-Face Interviews

The researcher arranged a meeting with the respective neonatal units to introduce herself and explain the study. She confirmed that the data collection is her responsibility and would not impede on any of the staff and their nursing responsibilities. The researcher asked permission that the nurse who admits a baby with gastroschisis to the neonatal intensive care unit should only brief the mother about the study when she is at the bedside. If the mother confirms that it will be acceptable, the researcher would be contacted with the information. Once the researcher was informed, she went to the unit where the mothers would be visiting their babies and waiting for them to end their visit before she introduced herself.

The researcher introduced herself and explained the nature of her study, and asked the mother if they would be interested in participating. If the mother showed interest, the researcher asked for her contact detail and promised to phone back within two days. The researcher also gave the mother her contact details and asked the mother to send her a message at any time if she decided against participation or wanted more information. The researcher indicated that the interview would be held around day two after the mother was admitted to the baby's bedside and became involved in the neonatal care of her baby.

If the mother indicated on a specific day that the researcher contacted her that she is not ready for the interview, the researcher would postpone the appointment for another two days or until the mother is ready.

The researcher contacted the mothers a day before the interview as a reminder and to reconfirm the time for the meeting. The researcher called the mothers on the day of the interview for confirmation and to inform them where she would meet the mothers~~.~~

The interviews for this research study were conducted in the participants' lodger ward, permitted by the ~~Unit Manager. A side room in the lodger room was provided by the Unit Manager for privacy and a do~~

not disturb sign was put on the door.

The voice recorder was tested before each interview and the participants were informed about its use. The voice recorder was placed in an area on the table that was not too noticeable but still enabled a clear recording. The researcher also ensured that the mother's name would not appear anywhere and that the interview would receive a numerical number and the particular date, time and hospital. The researcher again explained the aim of the study and only then the participants signed consent (view Annexure C).

Figure 1 is a representation of the side room used for the interviews. The participant and the researcher were seated around a table facing each other. The side room was quiet, and no noise disrupted the interviews.

Figure 2.1: Schematic presentation of sitting arrangement during the individual face-to-face interviews.

2.5.6. Interviewing Phase: Conducting The Individual Face-To-Face Interviews

During the interview phase in qualitative studies, the researcher will ask questions to collect data or information from the participants in such a manner that they provide information freely and in their own words (Polit & Beck 2018:510). The researcher conducted 11 individual face-to-face interviews and the same approach was followed for each interview to ensure trustworthy data.

Before starting the interview, the researcher again explained the process of data collection and confirmed the fact that there is no right or wrong answer; the participant should answer the question honestly and explain her experiences. If a question is unclear, the participant should also indicate it and the researcher would rephrase the question for clarity. The researcher informed the participants that she would make some notes on the paper if she wanted to remember something important during their conversation and debate. The participants were English-speaking and occasionally used words in Setswana and IsiSwati to express their emotions (view Chapter 3). These words were used for general expression of feelings and captured verbatim as such during the transcription of data. The participants who were overwhelmed by emotions and started crying were given a moment and asked if they were comfortable continuing with the interview and they agreed to continue with the interview. At the end of the interview, they were offered an opportunity to be referred to a social worker or a psychologist. An arrangement was made that in the case the researcher identifies the need for a referral, the researcher could use the internal system of referral. Then the researcher could also follow up with the participant that she is well after the emotional stress she experienced.

The researcher started the interviews with a general question about the baby’s condition on that day and encouraged the participant to tell her about the baby’s health problems. This approach aimed to ensure that the participants felt comfortable with the situation and focused on the questions that were systematically asked from general to specific, from barriers to enablers to recommendations.

The researcher started with an explanation of what barriers and enablers are before posing the general question namely:

What are the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis?

The researcher indicated to the participants that they do not need to answer the question immediately, but can think about the barriers and enablers experienced by them when they were involved in the neonatal intensive care of their babies. The probing questions were based on the above general question.

In this study, the researcher had to rephrase some of the questions for clarity and understanding by the participants. The researcher built a close relationship with the participants, resulting in sharing of detailed and honest information as the participants revealed the barriers and enablers they experienced when taking care of their babies in the NICU.

The interviews followed the suggested questions as indicated in the interview guide (view Annexure B). When probing didn’t provide new information, the researcher positively concluded the interview by asking the following: *‘is there anything else you want to tell me?* ‘Following that, the researcher thanked the participant and indicated that she might contact her if she required additional information. After the interviews, the researcher accompanied the participants back to the NICU.

The researcher conducted interviews until data saturation occurred. Data saturation occurs when themes and categories in the data become repetitive and redundant and no new information can be collected through further interviews (Pilot & Beck 2017:103). In this study, data saturation was reached on the 11th participant as there was no emergence of new information (view Chapter 3).

2.5.7. Use Of The Voice Recorder

Interview data can be voice recorded and stored to listen and re-listen to before transcription (Polit & Beck 2017:508). In this study, the interviews were voice recorded verbatim (word by word) and transcribed thence. The participants agreed to the voice recording before data collection, and these recordings were labelled according to the number of interviews, dates, and times to prevent the mixing of recordings.

2.5.8. Listening Skills And Interview Technique

A critical aspect of interviews was the listening skills the researcher used during data collection. According to Polit and Beck (2017:516), listening skills are imperative for collecting in-depth data. These skills include good listening to the information the participants shared, no interruption of the participants' stories and no asking of leading questions. In this study, the participants were allowed the freedom to answer the questions in an unhurried manner while the researcher listened attentively.

Clarification implies the use of follow-up questions to ensure that information is clear (Polit & Beck 2017:516). The researcher sought clarification in this study when statements were unclear or incomplete by asking: 'tell me more… '

Paraphrasing is viewed by Grove et al. (2017:268) as expressing the meaning or track of a conversation by using different words to achieve greater clarity. The researcher paraphrased some of the participants' answers such as for clarity and to come into agreement that the answers were interpreted in the way they were meant to indicate. One example was: … *' do you mean that it was difficult to*…. *'tell me why, please'*

Pauses and silences were used by the researcher to give the participants time to answer and set the pace during the interview. The researcher used nonspecific prompts such as '*mmhmm* ' to encourage the participants to continue with their answers.

2.5.9. Field Notes

Field notes are broad and interpretive notes made by the observer to record additional information to understand the data (Polit & Beck 2017:736 521). In this study, the researcher listened to the participants and made field notes through observations of the participants' behaviours and expressions. This was used during data analysis for a thick description of the findings (view Chapter 3).

The researcher used the following field notes according to the explanation of Polit and Beck (2017:736-737)

Descriptive notes, which are objective statements and information about the interviews. One example of a descriptive note is: *' the mother looks sad, she says seeing her baby in that ill condition breaks her heart. She says that she has never seen a baby who is born with intestines outside their belly. She indicated that once her baby has had an operation she will be able to look after her without fear* '.

Other descriptive notes*, the mother was shy and nervous but when she started talking about her baby, she became more relaxed.*

Personal notes which are applicable here about the researcher. The researcher's bubbly personality came in handy during data collection. Her friendly personality commenced from the setting up of appointments for the interviews which were done telephonically and even physically in other instances. The way the researcher approached the participants made the participants feel at ease. She always initiated small conversations before the formal interview which assisted in creating a friendly and comfortable environment for the process of data collection. The participants felt at ease and behaved naturally which in turn encouraged the participants to speak freely about their feelings and experiences. The researcher reassured the participants that privacy and confidentiality will be adhered to.

2.5.10. Post- Interview Procedure

Polit and Beck (2017:729) indicated that the researcher should listen to the recorded interview as soon as possible after the interview concluded for completeness and audibility. In this study, the researcher listed to the recordings as soon as possible after the interviews and found that they were audible for transcribing the information. The researcher did not need to arrange follow-up interviews to clarify information.

2.5.11. Researcher-Participant Relationship During Data Collection

According to Gray and Grove (2019:588), the relationship between the researcher and participants in qualitative research is important and influences the objectivity of data. In this study, the researcher created a respectful and honest environment for data collection by being open about the aims and objectives of the study. She negotiated the best possible date and time with the participants to accommodate their feelings and emotions. Throughout the study, the researcher professionally conducted herself and listened attentively to communication.

2.6. Data Management And Analysis

Data management implies that the researcher converts the collected data into smaller and more manageable pieces of information (Polit & Beck 2017:535). The researcher constructed from the recorded interview information to present findings that answered the research question (view Chapter 1). After collecting, the information regarding barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis, the researcher had data in the form of interviews and field notes. According to Polit and Beck (2017:530), the next step is data analysis to organise, transcribe and give meaning to the data.

2.6.1. The Process Of Data Analysis

Polit and Beck (2017:530-531) state that qualitative data analysis is an active and interactive process. The researcher initially listened to the recorded interviews immediately after the sessions to ensure audibility. Thereafter she listened and re-listened to the recordings to search for meaning and understanding. In the process of data analysis, the researcher fitted all the information together to making obvious and link together the barriers and enablers experienced by mothers involved in the neonatal intensive care of babies born with gastroschisis. The researcher listened to the verbatim audio recordings and transcribed the recordings as they are without manipulating the recorded data.

The researcher transcribed the audio recording after every interview, this was done to ensure that the researcher does not leave out any information that was captured through observations, this also ensured that the researcher transcribed every single word that was said by the participants in texts. The researcher used the five phases as explained by Yin (2016:186) during the process of data analysis (view Chapter 1). In this study the following process was used to analyse the data:

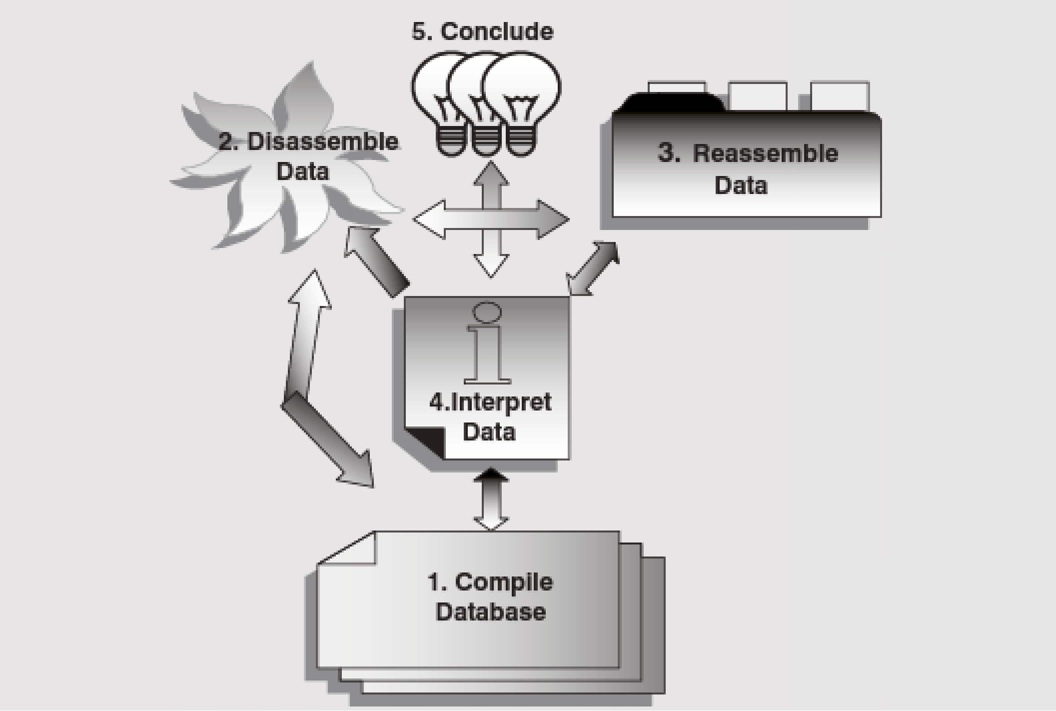

Figure 2.2: Example of Yin (2016:186) representing data analysis used in this study.

[Source: https://www.researchgate.net/figure/Yins-five-phases-of-analysis-and-their-interactions_fig1_318307677]

2.6.1.1. Compiling Data

Compiling data is the first phase of data analysis. Compiling means formally arranging all the notes in some useful order. The researcher gathered all the transcripts and read them against the audio recording from the face-to-face interviews. The researcher familiarised herself with the collected data together with field notes that were captured through observations by the researcher. The researcher carefully read the transcribed data and she was able to highlight similar information. This ensured that the researcher transcribed every single word that was said by the participants in the texts. The researcher used different colours for highlighting. This assisted the researcher to organise the data and to avoid working haphazardly during the process of data analysis.

2.6.1.2. Disassembling

This is the second phase of data analysis. It calls for the breaking down of the compiled data into smaller fragments or pieces, which may be considered a disassembling procedure. The researcher, with the assistance of an external coder, used Strauss and Corbin’s Grounded Theory for this process. They broke down the collected data, examined, compared, conceptualised and categorised it so that the data could be interpreted. This was done to develop categories and subcategories.

This phase of data analysis was repeated many times to ensure that the labels were adequately refined for the use of data analysis. The researcher and her assistant used different colours in the quotations to identify the experiences of the participants concerning the barriers and enablers they experience when involved in the Neonatal intensive care of their babies with gastroschisis. The highlighted quotes assisted in the formation of categories and subcategories. The following colours were used for the barriers: red was used to highlight the emotional barriers, purple for barriers related to the baby, green for barriers related to the healthcare system and orange for social barriers. Different colours were again used for the Enablers: Blue was used for emotional enablers, yellow for coping strategies and dark blue for opportunities to enable the mothers, additionally, colours used for the recommendations were pink for the healthcare system recommendations and brown for the recommendations to enable the mothers.

2.6.1.3. Reassembling

This is the third phase, and it is considered the reassembling procedure where the researcher uses substantive themes, based on combinations of disassembled items, to reorganise the fragments or pieces into different groupings and sequences than might have been in the original notes. The researcher and an external coder organised the data in a way that she would be able to develop themes. The data were first disassembled into smaller fragments and grouped to form themes. During analysis, qualitative researchers must distinguish between ideas that apply to all (or many) people and aspects of the experiences that are unique to participants, additionally, themes emerge from the data, and they often develop with categories of data but may also cut across them (Polit & Beck 2017: 537). The researcher and the external coder developed three themes from the quotations. The themes were formed from the highlighted barriers, enablers, and recommendations (view Chapter 3: Table 3.1).

2.6.1.4. Interpreting

This is the fourth phase of data analysis, which involves using the reassembled material to create a new narrative. The researcher, with the assistance of an external coder, used a table for the interpretation of the reassembled data. The table included Themes, Categories, and Subcategories (view Chapter 3: Table 3.1).

2.6.1.5. Concluding

Concluding is the fifth and final phase of data analysis. It calls for drawing conclusions from the entire study. Such conclusions should be related to the interpretation in the fourth phase and through it to all the other phases of the cycle. The researcher concluded the analysis based on all four phases of data analysis in Chapter 4.

2.7. Application Of Strategies To Ensure Trustworthiness

According to Polit and Beck (2017:747), trustworthiness refers to certain criteria that need to be applied to ensure that data and information in qualitative studies are accurate and representative. In Chapter 1 a detailed discussion was provided about the strategies that were used to ensure trustworthiness. Following is a summary of specific strategies that were used during data collection and analysis according to Lincoln and Guba (1985) in Polit and Beck (2017:559-560) (view Chapter 1: Section 13.7)

2.7.1. Credibility

Credibility refers to the integrity and believability of the data, and interpretation thereof (Brink et al. 2018:158). Credibility was ensured by following a plan to carry out the data as explained in Chapter 1 and this Chapter. Believability was further enhanced through prolonged engagement and persistent observation.

2.7.1.1. Prolonged Engagement

Prolonged engagement refers to spending sufficient time with the participants to obtain data to have an in-depth understanding of the information and ensure data saturation. In this study, the researcher took time during the interviews to collect the data and did not hurry the participants to tell their stories. The researcher also used probing to ensure that the information was correctly understood and the detail required to describe the barriers and enablers experienced by the mothers involved in the neonatal intensive care of their babies with gastroschisis.

After each interview, the researcher summarised the data to ensure that she understood it correctly to present the findings in a believable manner. The duration of the interviews was between 17 and 40 minutes, and sufficient time was allowed to build a trusting relationship to share credible information.

2.7.1.2. Persistant Observation

Persistent observation is when the researcher focuses intensely on the situation during data collection to ensure that data is correctly collected and recorded. In this study, the researcher used persistent observation during the conduction of the 11 interviews to explore the barriers and enablers experienced by mothers involved in the neonatal critical care of their babies with gastroschisis. Using this technique of credibility ensured that particular characteristics during the interviews provided depth to the data. The relevant characteristics in this study were the barriers and enablers.

2.7.2. Dependability

Polit & Beck (2018:416) state that dependability refers to the stability (reliability) of data over time and conditions. To provide evidence of consistency and reliability of the findings (Brink et al 2018:118). This study ensured dependability by using an audio recorder to ensure no occurrence of loss of information.

Dependability' refers to the provision of evidence such that if it were to be repeated with the same (or similar) participants in the same (or similar) context, its findings would be similar (Brink et al. 2018:159). For this study, dependability was ensured by using an audio recorder to ensure the safety of the collected data. Furthermore, a substantial description of all procedures followed the selection of participants, data collection and data analysis. The researcher in addition, consulted and discussed with her supervisors the process of data collection and interpretation.

2.7.3. Confirmability

Brink et al. (2018:159) Confirmability refers to the potential for congruency of data in terms of accuracy, relevance or meaning. It is concerned with establishing whether data represent the information provided by the participants and whether the interpretations are not fuelled by the researcher's imagination. The data must reflect the voice of the participants, and not the researcher's biases or perceptions. Polit & Beck (2018:416). Confirmability refers to objectivity as the potential for congruence between two or more independent people about the data's accuracy, relevance or meaning. Conformability is concerned with establishing that the data represent the information participants provided and that the interpretations of those data are not invented by the inquirer. For this criterion to be achieved, findings must reflect the participants' voices and the conditions of the inquiry, and not the researcher's biases or perspectives.

In this study, non-biased data were ensured by the assistance of the independent coder, who was given the transcribed data, original data, themes and subthemes from the research study and compared them with her own.

Polit and Beck (2018:416) assert that, for confirmability to be achieved, the findings have to reveal the participants' voices and not the researcher's perspectives. Conducting individual interviews during which the participants' voices were recorded, and transcribing those recorded interviews verbatim, confirmed that the collected data were indeed from the participants themselves. Where the researcher suspected that the information was similar between the two participants, the researcher listened to the recording more than once to ensure that the information was from one participant.

2.7.4. Transferability

Transferability, analogous to generalisability is the extent to which qualitative findings have applicability in other settings or groups. Polit & Beck (2018:416). Transferability refers to the ability to

apply the findings in other contexts or to other participants (Brink et al. 2018:159)
According to Polit & Beck (2018:416), transferability refers to the potential for extrapolation, which refers to the extent in which findings can be transferred to or have applicability in other settings or groups. The Lincoln and Guba (1985) framework noted in Polit and Beck(2018:416) indicated that, the investigator's responsibility is to provide sufficient descriptive data so that consumers can evaluate the applicability of the data to other contexts: 'Thus the naturalist cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether the transfer can be contemplated as a possibility' (Polit & Beck 2017:788). In this study, the researcher made an available comprehensive description of the setting and methods used in the research that will allow for evaluation, should the reader decide to apply the findings in another setting.

2.7.5. Authenticity

Authenticity refers to the extent to which researchers fairly and faithfully show a range of different realities (Polit & Beck 2017:418). Brink et al. (2018:160) refer to authenticity as the extent to which the researchers indicate a range of realities impartially and sincerely. For this study, the researcher and an external coder examined the condition of the tape recordings. The researcher ensured that the report is written to the extent that it conveys the feelings of the participants by using direct quotations as evidence. This will provide the readers with knowledge regarding the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. Data authenticity consisted of the audio-taped voice recordings of the participants during individual interviews and verbatim transcripts thereafter. The stated findings showed the true reflections of what emerged during the study.

2.8. Application Of Strategies For Specific Ethical Considerations

In Chapter 1, a detailed discussion was provided about the strategies that were used for ethical consideration. In this study, the researcher ensured that all the considerations discussed in Chapter 1 were applied. Throughout the discussions in this Chapter, ethical aspects were included. One specific aspect of ethical consideration the researcher wanted to highlight is the focus on the vulnerability of the mothers as participants. The researcher regarded the participants as a vulnerable group since they were mothers of babies with gastroschisis. The congenital defect in itself is extensive and appalling to experience as a mother (view Chapter 3). The participants had to cope with the defect, taking care of their sick babies in a threatening environment and were not able to hold or cuddle the baby. The researcher was exceptionally careful and sensitive during data collection not to add further emotional distress, as explained in this Chapter. The researcher also informed the participants that they could withdraw from the interview anytime without consequences for them or their babies. The researcher also communicated to the participants that she could refer them for psychological support should the need arise. None of the participants withdrew from the interviews nor asked for a referral.

2.9. Summary

This chapter provided a discussion of the methodology and the research design used during data collection. In-depth detail was provided about the method of data collection and the way the data were analysed. Chapter 3 provides an outline of the findings, followed by a discussion and literature control of the findings.

3. DISCUSSION OF FINDINGS AND LITERATURE CONTROL

3.1. Introduction

In the previous chapter, the methodology was fully discussed. This chapter will present and discuss the findings of the analysed data, supported by relevant evidence from recent literature. The study aimed to explore and describe barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The findings of this study were derived from data which were collected through semi-structured face-to-face interviews. The overall research question formulated for this study was **'What are the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis? '**

3.2. Demographic Information Of The Participants

The sample consisted of 11 mothers who gave birth to babies with gastroschisis and were involved in their neonatal intensive care. The duration of each interview was between 17 and 40 minutes (view Chapter 2).

The 11 participants interviewed were aged between 18 and 36 years, and only one was married. Their ethnicity was black and the majority were referrals from peripheral hospitals. One mother was a foreigner, and the others were from South Africa, originating from Gauteng, Mpumalanga, North West and Limpopo. Some mothers were primigravida, and others were multiparas.

3.3. Findings And Literature Control

The following questions were posed during the face-to-face interviews.

To explore the barriers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis, the question was:
What makes it difficult to take care of your baby while he/she is in the neonatal intensive care unit?

To explore the enablers experienced by mothers involved in the neonatal intensive care of their babies born with gastroschisis, the question was:
What makes it easier to take care of your baby while he/she is in the neonatal intensive care unit?

When the researcher visited the mothers for the first time, she asked about the gender of the baby. During the interviews, she used he/him or she/her.

The researcher used the five phases of data analysis as described by Yin (2016:186) (view Chapter 2). Verbatim extracts from collected and transcribed data were used as supporting quotes during discussions of the categories and subcategories in this chapter.

The themes were the barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis, enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis and recommendations.

Table 3.1 summarises the themes, categories and subcategories experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

Table 3.1: Summary of themes, categories, and subcategories.

THEMES	CATEGORIES	SUBCATEGORIES
1. Barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis	1.1. Emotional barriers	1.1.1. Emotional experiences related to the initial diagnosis (fear, shock, trauma)
		1.1.2. Emotional experiences related to harming the baby (hurt)
		1.1.3. Emotional experiences related to the baby's condition (fear, sadness, trauma, guilt, anger)
	1.2. Barriers related to the baby	1.2.1. Barriers related to the condition of the baby
		1.2.2. Medical equipment-related barriers
	1.3. Healthcare system- related barriers	1.3.1. Barriers related to access to the baby
		1.3.2. Healthcare-related barriers
	1.4. Social barriers	1.4.1. Removed from their families and emotional and other effects on the family
2. Enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis neonatal	2.1. Emotional enablers	2.1.1. Hope and relief
	2.2. Coping strategies	2.2.1. Internal coping
		2.2.2. External coping: Family support
		2.2.3. External coping: Healthcare support
	2.3. Opportunities to enable mothers	2.3.1. Opportunities to be with the baby
		2.3.2. Opportunities to bond with the baby
		2.3.3. Opportunities to take care of the baby
3. Recommendations of mothers involved in the neonatal intensive care of their babies with gastroschisis	3.1. Recommendations for the healthcare system	
	3.2. Recommendations to enable mothers	3.2.1. Opportunities to be with the baby
		3.2.2. Opportunities to bond with the baby
		3.2.3. Opportunities to take care of the baby

Findings are discussed in the next session according to the themes with associated categories and subcategories.

3.4. Discussion Of Findings

Themes are discussed in terms of categories and subcategories and verbatim quotes from the 11 transcripts are used to ensure the trustworthiness of the discussions and findings. Participants were referred to by using a combination of their initials and the number of the interview conducted which appears in brackets at the end of each quotation to maintain participants' confidentiality.

3.4.1. Theme 1

Barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis

According to the Oxford dictionary (2020:47), a barrier is an obstacle that prevents people from communicating, making progress, or understanding something. In this study, barriers were regarded as aspects or obstacles that prevent the mothers from becoming involved in the neonatal intensive care of their babies with gastroschisis.

Table 3.2: Categories and subcategories for Theme 1: Barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

Table 3.2: Categories and subcategories for Theme 1.

THEMES	CATEGORIES	SUBCATEGORIES
1. Barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis	1.1. Emotional barriers	1.1.1. Emotional experiences related to the initial diagnosis (fear, shock, trauma)
		1.1.2. Emotional experiences related to harming the baby (hurt)
		1.1.3. Emotional experiences related to the baby's condition (fear, sadness, trauma, guilt, anger)
	1.2. Barriers related to the baby	1.2.1. Barriers related to the condition of the baby
		1.2.2. Medical equipment-related barriers
	1.3. Healthcare system- related barriers	1.3.1. Barriers related to access to the baby
		1.3.2. Healthcare-related barriers
	1.4. Social barriers	1.4.1. Removed from their families and emotional and other effects on the family

For this theme, four categories are identified. Each of the categories and subcategories is discussed below.

The first category focused on the emotional barriers experienced by the mothers when they are involved in the neonatal intensive care of their babies with gastroschisis**.**

3.4.1.1. Category 1 – Emotional Barriers

Emotional barriers are referred to as the walls that obstruct perception, actions and communication with other individuals (Radhika 2020:1). The first subcategory for emotional barriers relays to the emotional experiences related to the initial diagnosis (fear, shock, and trauma).

- **Subcategory 1.1.1: Emotional experiences related to the initial diagnosis (disbelief, fear, shock, trauma)**

Ordinarily, when a woman is pregnant, she starts to form an attachment with her unborn baby, where the mother starts to connect with her baby by either, singing, rubbing her belly, or even talking to her baby. The mother starts to plan and prepare for the delivery and the care of a healthy baby (Mazibuko, Ramukumba & Ngwenya (2022:1). Which is always not the case. The participants in this study, except for one mother, were not prepared for babies born with gastroschisis. According to Lomotey, Bam, Diji, Asante, Asante, et al. 2020:150), mothers are usually psychologically and physically unprepared for motherhood and this may lead to an inability to identify with their babies even though they had anticipated becoming mothers. This unpreparedness together with the realisation that their babies are born with gastroschisis, resulted in emotional barriers, which the mothers experienced as fear, shock and trauma when confronted with the diagnosis. The following quotes were derived from the participants when they were expressing their emotional experiences concerning the initial diagnosis:

"(Exhale) it breaks my heart because I have never seen something like that Ngoba ngiyacala kuyibona lento. (Because it is my first time seeing that thing). Lamathumbu langaphandle. (The intestines that are outside). Ngiyasaba vele. (Of course, I am afraid)." (P1: C)

"When I gave birth, when I saw the intestines outside, Like, like I was so shocked, like what's going on, is the baby okay, but I saw like the baby was okay because he was crying and breathing. But when I go to 24, ward 24 like seeing the child with, with that plastic thing and the whole, the whole intestines. I was No! like what is this"? (P4: D)

"Like at first, ya (yes) I was traumatised when I see him. Because (pause) that was the first thing that I experienced in my life. Like I did not know that the baby will come or a human being- Will be born with intestines outside." (P6: L)

"For carrying her. Yes. Mmhmm! I was scared of the intestines." (P9: C)

⇒ **Discussion**

In this study, the mothers expected to give birth to healthy babies and were caught unexpectedly with a baby born with a defect. The fact that the babies were born with gastroschisis acts as an emotional barrier because they experienced fear, shock and trauma when seeing the babies for the first time.

The study by Kidane, Shamebo, Ntaganda, Petroze, McNatt, et al. (2022:1) reports that mothers expressed fear and surprise as their first reactions when seeing their babies born with gastroschisis. It is sometimes a normal reaction that the sense of fear transitions from distress to fear of losing the baby as time spent in the NICU increases (Wang, Ma, Meng & Zhou 2021:7065).

The above quotes indicated that the participants were in disbelief, fear, shock and traumatised when they saw their babies for the first time. The participants mentioned that they had never seen a baby with gastroschisis before and that it was a shocking and traumatic experience when seeing their babies with intestines visible outside the body. As much as the participants were shocked and afraid, one participant said she was consoled by the fact that her baby was alive because the baby was crying and breathing. Another participant indicated that she was traumatised and did not know if the baby will be a human thing. These findings can be supported by the results of the study conducted by Radhika (2020:6), who refers to emotional experiences and trauma as the response to deeply distressing or disturbing events that overwhelm the individual.

- **Subcategory 1.1.2: Emotional experiences related to the baby's condition (Fear, sadness, trauma, guilt, anger)**

Rihan, Mohamadeen, Zayadneh, Hilal, Rashid, et al. (2021:1) indicated that mothers with babies in the NICU may experience emotional reactions such as grief, sadness, guilt, fear, anger, loss of self-esteem, and a sense of failure. Mothers of babies with gastroschisis have to deal with the emotional experiences of the defect as well as the stressful NICU environment (Kidane et al. 2022:5-6).

The following quotes display the participants' emotional experiences of fear, sadness, trauma, guilt, and anger related to the baby's condition:

"What is difficult is when I see my baby- Is when I hear my baby cry. And obvious I will have that mind that my baby no! is in pain. He is in a lot of pain. And then I feel like I can cry, and I feel so emotional." It, it affected me emotionally- Physically- and (pause) like the whole me. I feel like staying here, my baby with that medical, (Stutter) medical condition. I feel like this whole thing

making me mad. Making me crazy because of staying here every after two hours seeing the baby with that condition, making me feel so sad. What makes me, what makes me angry the most- It is when I see my baby (sigh) when I see my baby in that condition. And when I sleep in, in this hospital. This hospital bed, the whole food, the whole thing uhm, uhm! It is making me sad and making me, I feel like I, I got anger." (P4: D)

"Yhoo! (Exhale) Sometimes I (stutter) I have mixed emotions. But I have to be strong. Sometimes I go there, and I find that they have put a pipe on him, and he is bleeding a bit, then that will be a problem for me. I will be very sad, then maybe it's hurting him or, (pauses) like maybe I might say they should help him maybe remove it, but I cannot say it because they are helping him. "Yoh! Sometimes it makes me sad. Eh! Over-whelmed, having mixed emotions." (P5: M)

"Ya" (yes) to, to (stutters) yhooo! (Sighs) to feed a baby with gastroschisis like to be like to have a baby like it is not easy. To, to (stutters) to be with a baby who has gastroschisis, like I was traumatised. Like yhooo (sighs) I was always thinking about my baby thinking will he be fine, like something like that." Like to say okay will he survive? I was asking myself those questions every night. Like I was asking myself every night, I was crying. Day and night. Yhooo! yhooo! eh! staying at hospital is traumatizing Yoh! (Exhales)." (P6: L)

The findings in the quotes above are in line with the findings in a study by Lee and Ahn (2020:5), who reported that mothers felt deeply frustrated, anxious and concerned about the uncertain future of their sick babies, including the thought that their child may die. Additionally, Tees and Pool (2018:1) documented a traumatic event as any incident which is experienced suddenly and unexpectedly and results in emotional trauma and shock.

North Tees and Hartlepool (2018:1) further explain that shock presents itself in the form of disbelief, the experience appears unreal, numbness and a slow realisation of what has happened. The participants in this study experienced fear of losing their baby and feelings of helplessness accompanied by losing control and sadness about the possible loss of life. One participant in this study wondered if her baby would survive. It was sad for her as she could not stop crying.

Sadness is an emotion triggered by loss (Isaacs & Andipatin 2020:8). The quotes also expressed that the participants felt saddened by their babies' appearance and the fact that their babies weren't getting better as they were always in the hospital. Feelings of helplessness are evident in the quotes, as the participants couldn't help their babies when they were crying. The emotional state of the participants was affected as they experienced anger. The anger manifested as a result of the condition of the baby and the hospital set up, followed by feelings of guilt (Mazibuko et al. 2022:2). One mother expressed that she blames herself for rushing to sleep with a man at a young age. Isaacs and Andipatin (2020:8) defines guilt as a sense of responsibility for harmful actions, feelings of having done wrong and anger, which is the negative associated with emotional responses.

However, the following quote displays how one participant had a different perception regarding the emotional experiences related to the baby's condition:

"Yes, that's what gave, like my child is strong, he gives them hope like, I am gonna be fine. He is fighting for himself, even though we are not. (Sigh) I am weak like I can't fight for him. Every day it's a new result, I never came here and cry. Ever since this situation started, I have never cried, it's only now that I have cried, I never." (P7: D)

The participant was encouraged when she saw her baby's progress and that his condition was improving daily, which gave her hope that he'll eventually recover. She indicated in the quote that she felt powerless, but her baby is strong and fighting and that gave her hope.

3.4.1.2. Category 1.2: Barriers Related To The Baby

This category relates to barriers experienced by the mothers and related to the baby.

- **Subcategory 1.2.1: Barriers related to the condition of the baby.**

Understanding the diagnosis and possible journey ahead can be overwhelming for parents and often left them feeling powerless (Hinton, Locock, Long and Knight, 2018:5). Lomotey et al. (2020:151) reported that the condition of infants and tube feeding have been identified as sources of stress for mothers.

The following quotes reveal the barriers related to the condition of the baby that the mothers experienced when involved in the neonatal intensive care of their babies.

"To hold (stutter) to hold her. Yes, to hold the baby. Uhm! Mm… I think because of the condition of the baby. She was in a bad condition. Mm… I thought I was not allowed". (P11: L)

"Is to hold him. Bond with him. Like ya (yes), but I cannot. Because he was still in a critical condition." (P6: L)

"The, the, eish (exclaim) like you, you don't get to bath your child, like you can't bath your child, I can't cuddle him because he is busy, like the thing is hanging there. So, I can't, I can't carry, like since I gave birth to him I, I never carried, that's the most emotional thing that is been troubling me." (P7: D)

"No Nurse. It, it was so difficult. To do it, because even to clean the baby No, the Doctors would say, just say no just leave, we will do it. Yes, they will say we will do it for you, just leave the baby, and even to hold him I was not even holding him. Ahh! (exhale) it was so painful, (giggle) sometimes the Doctor will say, "go mama is now time for you to go, go to the mother's lodge." (P8: K)

⇒ **Discussion**

The participants experienced the condition of their babies as a barrier to becoming involved in the neonatal intensive care of their babies. The barriers experienced by the participants was their babies' medical condition where the intestines were visible outside their bodies which hindered their involvement in neonatal intensive care.

The participants mentioned that their babies were critically ill or in poor condition, which made it difficult for them to hold, cuddle or bond with the babies, which was also a finding in the study of Peters, Kaur, Dogra, Kaur, Malik, et al. (2022:871). According to Peters et al. (2022:872,873), the stress mothers experience is multifaceted, relates to the condition of the babies and creates many fears in the mothers. In the above quotes, one participant indicated that gastroschisis ('*the thing is hanging there')* is an emotional thing and troubling her. This participant especially said that the condition of the baby prevent her from bathing him.

One participant stated that it was difficult to become involved in the care, even cleaning her baby was not allowed and that troubled her. This participant said that the doctors told her it was not allowed and that she should leave her baby and return to the lodger room as they will care of the baby. She regarded this barrier related to her baby as a painful experience. This finding is similar to the results of Hinton et al. (2018:5), who explained that parents should not be dismissed from the care environment as it results in later challenges regarding bonding and fulfilling a maternal role.

- **Subcategory 1.2.2: Medical equipment-related barriers.**

The mother's first contact with her baby born with gastroschisis impacts her life as her baby is in an unknown environment, critically ill and unstable and strange equipment is used in caring for the baby (Santos & Martins 2017:4076). In this study, the participants indicated that medical equipment is a barrier to becoming involved in caring for their babies. The babies of the participants were admitted to NICU and nursed either on radiant warmers or incubators, oxygen was administrated and infusion pumps were used. The lighting in the NICU and the constant noise from the monitor alarms contributed to the participants' feelings of stress and anxiety. This finding coincided with Lomotey et al. (2020:150), who reported that the physical environment in the NICU is characterised by monitoring equipment, tubes, and wires connected to the infant, noises, and chemical scents.

Wang et al. (2021:7067) also reported that in babies with gastroschisis confined to incubators, the mothers experienced feelings of alienation and found it difficult to overcome the physical barriers to becoming involved in the care.

The following quotes revealed the experiences of mothers regarding medical equipment-related barriers:

"Because always in the machines. For breathing. Oh! She was always in incubator. And in that oxygen. So, they told me not to move the baby cause that oxygen will move." (P3: D)

"The barriers is when I get out of my ward- And go straight to the 24 ward-But when I enter, seeing a child- With hav… with heavily breathing. Stomach outside- The whole process, the whole machines, big machines. That's making me stop, that is what making me stop. Seeing the baby. The pressure, machines. No, look the problem is the machines. I hate machines. The whole sound of the machines, the whole process, the whole, the whole thing about machines. Yes, (Stutter) So, it will make, it will be it easier if that they remove those machines and hide them (giggles) so that I cannot see them." (P4: D)

" (Sigh) I am just, (starter) I am still scared, to hold him- Or to change his nappy. Since he is on machines. You know. I do not know how to shift those, those wires on him. Sometimes he is just irritated and try to grab- Those wires on him. So, that makes me a bit scared the pipes around him, the machines, I make sure that I do not even make a mistake. ". (P5: M)

⇒ **Discussion:**

The use of the intensive care unit equipment in the NICU was something that the participants were not familiar with, and recognised these as barriers. These medical equipment related-barriers made it difficult for mothers to exercise their maternal roles as they were afraid of hurting and compromising their babies' health, who depended on the use of the equipment. The different types of equipment scared the mothers because of how they saw it in use on their babies. Mengesha, Amare, Asfaw, Mulugeta, Mitiku, et al. (2022:1) agreed that the NICU is necessary to save the lives of sick neonates, however, parents are challenged by the stressful environment**.** Furthermore, Santos and Martins (2017:4076) stated that the equipment in the NICU makes this environment impersonal and stressful.

In this study, the participants reported that the incubators and the oxygen used in the incubators prevent them from getting involved in the care, as well as the wires and pipes form barriers to handling as the participants are afraid of making mistakes. One participant expressed her disapproval of the machines strongly.

3.4.1.3. Category 1.3: Healthcare System-Related Barriers

The next category discusses the healthcare system-related barriers experienced by the participants. Two subcategories were identified.

- **Subcategory 1.3.1: Barriers related to access to the baby.**

According to Lomotey et al. (2020:150), a baby born with gastroschisis is usually separated from the mother immediately after birth and admitted to a NICU for specialised care.

In this study, the babies born with gastroschisis were mostly from peripheral hospitals which did not have paediatric surgical specialists working at the particular healthcare facility, and that necessitated separation from the mother and admission to another facility.

The participants in this study experienced separation from their babies as access-related healthcare barriers as they were cared for in the NICU. Several participants were given accommodation in the lodger ward and then struggled with the challenges of limited time to be with their babies and sleep deprivation as they had to wake up more than once in the middle of the night and walk from the lodger ward to the NICU. The advantage of being offered accommodation in a lodger facility is noted in the findings of Lewis, Andrews, Shenberger, Betancourt, Fink, et al. (2019:7), as this facilitated visitation, alleviates the effort required to travel, and relieves the financial burden on parents.

The following quotes were derived from the participants' quotes when they narrated their feelings concerning access to their babies.

"(Clicks tongue) because they will give me a certain time. (Stutter) They didn't give me the whole day to spend with my baby because of eh… the, (pause) because they, as the nurses - They have time to take care of the baby and myself, I have time to take care of my baby." (P2: L)

"No, because they give, they give us 30 minutes. To see our babies." (P4: D)

"I will be like the time they have given me is very small - You know, and sometimes (sigh) I find him sleeping And when I leave, he wakes up and opens up his eyes. After I have left." (P5: M)

" (Pause) the, (stutter) the only (giggles) thing that makes it to be difficult is just we wake up- Every after two hours- You have to wake up. That's the thing that (sigh), am not used to it here, you can never get used to waking up after two hours you wake up. And then you, uhm! You (stutter) sleep, we sleep in the mother lodge. You have to come here- At night (sigh) and the day- Like, the rotation- "Ya" (Yes). The time, eish! (Exhale) The sleepless nights, that is the only thing that makes it difficult." (P7: D)

"I am stressed. Because I see her maybe after two weeks." (P9: F)

"I have heard about the lodge, the lodge eh! The lodge room for the mothers. But they said it is only available for the mothers who are breastfeeding but at the moment my child can't breastfeed because they are still taking out the green stuff." (P10: A)

⇒ **Discussion:**

The barriers faced by the participants made it unfavourable for them to interact and bond with their babies. It was noted in this study that the mothers felt the need to be with their babies throughout their hospitalisation but they had limited access and experienced accommodation restrictions. It was also a finding in the study conducted by Mengesha, et al. (2022:125) that mothers who were unable to be accommodated in a lodger room experienced access to the healthcare facility as a challenge and a barrier to overcome. Mörelius, Olsson and Sahlén (2020:1) reported that separation between mothers and their sick infants in the NICU occurred commonly as many parents did not have the opportunity to stay close to the healthcare facility, and be with their sick babies around the clock.

Trumello, Candelori, Cofini, Cimino, Cerniglia, et al. (2018:2) noted that separation and exclusion result in a lack of physical and emotional closeness, which are fundamental factors in the early relationship between parents and the newborn infant. In this study, the participants experienced exclusion by the staff because when they wanted to be involved in the care of their babies as they were not permitted or asked to leave. One participant indicated that she was excluded from lodging in and staying close to her baby because she was not breastfeeding as her baby was not breastfeeding yet.

- **Subcategory 1.3.2: Healthcare-related barriers.**

Abeasi and Emelife (2020:25) indicated in their study that mothers felt they were overly restricted in taking care of their babies, especially when they were ordered not to do certain activities. In this study, mothers had to seek permission or wait to be given a directive before they could become involved in the care of their babies.

Kidane et al. (2022:11) mentioned that a shortage of skilled professionals and a lack of integration in programmes influence quality care for babies with gastroschisis and maternal involvement in the NICU.

The following quotes reveals how the shortage of staff and internal arrangements at healthcare facilities affected the participants and became a barrier:

"It affected me badly because of when my baby was in isolation, there was not enough care for her. The nurses (stutter) they will, they will take a nurse to look after her - But that Nurse will be in another ward, so, so may take more time in another ward before coming to my baby- There was a tube that was supposed to be suctioned I think it was for oxygen maybe, I forgot what its name is. For oxygen when it gets filled with secretions it must be suctioned. So, that tube will be filled with a lot of secretions, then the nurse would come and suction it, sometimes she won't be able to do so as she will be overwhelmed with other activities." (P2: L)

These subsequence quotes reveal how difficulties in communicating with the healthcare staff members were seen as barriers by the participants:

"No, they didn't say anything but, I did tell myself like No! like this time they are going to stitch him because of those intestines are so small." (P4: D)

"Yes, I do sometimes ask them, but others would say eh, the Doctor will come, you will ask the Doctor then the Doctor does not come." (P5: M)

One participant revealed the attitude of the nurse a barrier and in the end she has developed some fear for a particular nurse:

"Okay, like, if you want (stammers) if you want, you know mother to mother, like if, (clicks tongue) mother to mother to, to a son, And the nurses will block you like they say don't do this, Don't do like this, you know, (sigh) so it hurts us, cause is something that is not good for us. I think they have to tell us in a certain way, not in a harsh, harsh like- Sometimes you have some

> *fear and you (stutter) if myself I fear a lot some of the nurses (stutter) I see this Nurse I am afraid." (P8: K)*

⇒ **Discussion:**

Communication in a healthcare system between staff and patients is one of the aspects that influence the healthcare a patient receives. A study by Hinton et al. (2018:6) highlighted the importance of clear and ongoing communication between parents and the multidisciplinary teams who take care of sick babies. For parents to become involved in the care of their sick babies, it is important to listen to them, encourage them to become part of the care team and support them in finding a role for themselves in the healthcare of their babies (Hinton et al. 2018:6). According to Trumello et al. (2018:6), healthcare should include that the mothers stay near to their babies, be allowed to fulfil a nurturing role, and interact with the baby.

In this study, mothers felt left out as they were not involved in information sharing about their babies' health. The lack of involving the mothers in the healthcare, treatment and management of their babies together with the attitude of some staff members made mothers feel overlooked. Their quotes reflected both nurses and doctors were involved in poor information sharing, which concurs with the statement of Rihan et al. (2021:2) a finding in their study that some parents were displeased with their doctors' attitude and considered them to be a source of pain and anger because they did not talk to them.

3.4.1.4. Category 1.4: Social Barriers

The last category concerning barriers experienced by mothers involved in the neonatal intensive care of their babies was identified as social barriers. For social barriers, one subcategory was formulated and will be discussed.

- **Subcategory 1.4.1: Removed from their families and emotional and other effects on the family.**

Most mothers in this study came as referrals from other hospitals which were far from the referred hospital. This became a challenge for them as they were separated from their loved ones, and they were now unable to see their families as often as they used to. The only time they could interact with their families was when their families visited them in the hospital. These mothers have other babies or children at home who were taken care of by other family members.

The hospital stay and limited access to their babies in NICU pose additional emotional stress to the mothers even though they were also in the hospital, they were often sad because they did not get to spend more time by their babies' bedsides. Whereas if they were at home, they would be with their babies full time, taking care of them together with the other children who were now left at home.

Veronez, Nab, Corrêa and Higarashi (2017:6) explained that the anxiety expressed by the mothers about their sick and hospitalised babies might influence their social circumstances and concerns about their other children at home, the neglected household chores and marital conflicts often keep the mothers away from the baby in the hospital, or sometimes even force discharge. In addition, Veronez et al. (2017:8) indicated that extended maternal stay in the hospital usually exacerbates emotions of impatience, anxiety, and stress.

The following quotes revealed how being away from home and the admission of their babies to the NICU affected the emotions of the mothers:

"Yes, I am okay because it's far. Rustenburg is very far- You know, I cannot expect them to come here, to check up on me every day. If they do have a chance, if they do have the time to come here, they will come." (P5: M)

"I have three kids at home- Which are going to school- So, I am used to being with my child. With my children (Sobbing) and now I have to be here. Taking care of their younger brother. The relatives are there, my mother is there. Everyone is there, but (pause) it's not the same as for me not to be there-They miss me a lot. You have to wait and wait and wait while you wait you think about the other kids." (P7: D)

"I don't have one child, I have another who is four years old, she also needs me, so now, it's something that is always paining me here, I don't even get sleep thinking of that baby that I left there. My families are in Zimbabwe and here am just alone (exhale) me. (P8: K)

⇒ **Discussion:**

Lewis et al. (2019:7) indicated in the findings of their study that, many mothers found it challenging to balance time spent in the NICU with their other obligations and children. Rihan et al. (2021:2) revealed that mothers of babies in the NICU must address multiple challenges, such as dealing with people and medical staff in the NICU and handling their relationships. The study of Rihan et al. (2021:3) further mentioned that it is common for parents to have disrupted lifestyles at home due to stressful conditions.

In this study, mothers did not have the opportunity of being in the lodger ward to be close to their babies in the NICU and occasionally visit the ones left at home. The absence of participants from their homes affected them negatively as it added to the already existing challenges of being in the hospital with a sick baby whom the family members are trying to understand the condition. However, one mother was practical regarding the hospitalisation of her baby. She said: "*I had to sit down and say okay, I am not going back home*," and she consoled herself by saying she will go home soon because she cannot just expect her baby to recover over a short period of time. She said she had to wait and whilst waiting she was also thinking of her other children who are left at home.

3.4.2. Theme 2

Enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis

To enable is defined as giving someone the means or authority to do something, to make something possible (Oxford dictionary 2020:200). In this study, enablers are regarded as the aspects that make it easier for mothers to be involved in neonatal intensive care of their babies with gastroschisis.

Table 3.3: Categories and subcategories for theme 2.

THEMES	CATEGORIES	SUBCATEGORIES
2. Enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis	2.1. Emotional enablers	2.1.1. Hope and relief
	2.2. Coping strategies	2.2.1. Internal coping
		2.2.2. External coping: Family support
		2.2.3. External coping: Healthcare Support
	2.3. Opportunities to enable mothers	2.3.1. Opportunities to be with the baby
		2.3.2. Opportunities to bond with the Baby
		2.3.3. Opportunities to take care of the Baby

For this theme, three categories are identified. Each category and subcategory are discussed below.

The first category focuses on emotional enablers.

3.4.2.1. Category 2.1: Emotional Enablers

According to Garwood (2011:162), enablers refer to something or someone that makes it possible for a particular event to happen or be done. (Oxford dictionary (2020:200). Defines enable as giving someone the means or authority to do something, to make something possible. Emotional is defined as relating to feelings or how to control them (Longman Dictionary).

- **Subcategory 2.1.1: Hope and relief.**

In the study of Rihan et al. (2022:1), improvement in the health of the babies created feelings of hopefulness in the mothers.

In this study, the participants were hopeful that their babies will eventually get well and that their defect (gastroschisis) will be corrected. They were relieved when they saw that there was progress and that the abnormality was slowly getting corrected as compared to when their babies were first admitted to the NICU. Hope and relief are what kept them going as they kept believing that soon they will be able to go home with their babies. Below are the quotes from some of the mothers:

“Then I was able to calm down and realised that it means my baby will also be all right- Once my baby is operated, I will be able to take care of her.” (P1: C)

“I am so relieved like yhooo! (Exhales) finally, my baby is gonna be, is gonna be fine and that thing, that scary thing (pause) the intestines and the whole process, intestines are inside, and I don’t see them.” (P4: D)

”I do have hope that he is going to be well.” (P5: M)

“Ya (yes) she gave that hope, like I started to accept, to say okay fine. So, now like I am feeling much better.” (P6: L)

⇒ **Discussion:**

Hinton et al. (2018: 6) reported that support from other parents who had been through similar experiences (either online or face-to-face) was described as a crucial factor in helping parents cope and understand more about their baby’s diagnosis. One mother in this current study verbalised how another mother gave her hope when she told her that her baby had the same condition and that now they were ready to be discharged because the baby was doing well post-surgery, that’s when the mother in this study realised that gastroschisis does get corrected.

“But I got help from another girl, I found that girl in that ward. Her baby was born with gastroschisis. So, that was the time I accepted. That girl told me that my baby was like your baby, but you

> *see now he is fine. I then said okay! This thing is healed, like the will be fine, like I started to accept the situation."*

Kidane et al. (2022:5-6) reported that mothers in their study had hope for their babies when they realised that their conditions were improving and surgery performed to relocate the intestines to the intra-abdominal space. The participants in this study had similar views which were met with relief that in the end, they will be able to take care of their babies.

3.4.2.2. Category 2.2: Coping Strategies

According to Takács, Takács, Kárász, Horváth and Oláh (2021:2), coping strategies define efforts to regulate emotions, behaviours, cognitions and environmental aspects in response to the stress of everyday events. Each situation requires the use of a specific coping strategy. Coping strategies have a great impact on well-being, furthermore, an assessment process designed to respond to external and internal challenges. Freire, Ferradás, Regueiro, Rodríguez, Valle, et al. (2020:2) define coping as the cognitive and behavioural efforts employed in response to external or internal demands that the individual deems to be threats to their well-being. Additionally, Lazarus and Folkman (1984) in Stanislawski (2019:2) distinguished two basic coping categories, i.e., problem-focused and emotion-focused, as responses aimed at 'managing or altering the problem causing the distress' and 'regulating emotional responses to the problem,' respectively.

- **Subcategory 2.2.1: Internal coping**

The participants in this study were all religious and had faith in God that their babies will get well, they regarded this as inner strength and coping. Rafael-Gutiérrez, García, Prellezo, Paulí, Del-Castillo, and Sánchez. (2020:446) found that for many parents, constant praying offered them a sense of calm, hope, acceptance and coping. The participants in the present study personally found comfort in prayer and communicating with God which helped them to also accept the situation they were in. Rihan et al. (2021:7) reported that one of the most frequent reports of coping referred to reliance on God's mercy. In the following quotes, the participants narrate how they ended up accepting the situation they were in and how prayer played a big role during the hospitalisation of their babies with gastroschisis.

> *"So, I just accept that they are helping him, so I have accept- But I do tell myself that he is going to be well, I do pray for him almost every day, all day. Ya.' (P5: M)*

> *"Because those are in the hands of the professionals like if a doctor said the baby is not well, there is nothing I can do about it. The thing that I must do I (stutter) I must accept, so that my baby*

can be fine, so that when he goes home, he will be in a good condition- But I got help- From another girl, I found that girl in that ward. Her baby was born with gastroschisis. Like, that time I saw that baby and that baby was already healed. So, that was the time that I accepted. That girl told me that my baby was like your baby, but you see now he is fine. I then said OKAY! This thing (pause) is healed like, the baby will be fine like I started to accept the situation." (P6: L)

"Ee (Yes) I have told myself that this is what I have to deal with so, (pause) my baby safety comes first, My baby's recovery, eh! Recovery comes first, I have to be there for him. So, I can't say I have any- So, I just pray that my baby recovers so, that I can go home, take care of them and my other kids. (P7: D)

In this study, it is evident that the mothers had made peace with the admission of their babies as they had to learn how important it is for their babies to remain in NICU until the doctors were satisfied with their progress and recovery. The participants got accustomed to how things are done in NICU and they ended up getting involved in the care and routine. Santos and Martins (2017:4076) revealed that during hospitalisation the mothers were initially were confused and experienced ambivalent feelings. However, living with their babies with gastroschisis in the NICU allowed them to become more familiar with the environment and activities and were able to identify the importance of the environment for the maintenance of the baby's life. What also assisted the participants in this study is the fact that the mothers with babies born with gastroschisis had gone through similar challenges. Gutiérrez et al. (2020:444) noted that the mothers' conversations with each helped them to accept their babies' conditions, and gave them internal strength and the ability to parents support parents whose own children have also been admitted into the NICU.

- **Subcategory 2.2.2: External coping: Family support**

The support of family members assisted the participants in this study to cope with having a sick baby admitted into the NICU because the family constantly kept in touch through phone calls to check how the babies and the participants were doing. The family members rarely visited the hospital because of financial constraints as the referral hospital was out of their province yet, that did not discourage the family members from still offering their support remotely as they couldn't do so physically. This statement is in line with the study by Flacking et al. (2021:3121), which emphasized the importance that mothers should show their babies and talk about them with 'important others', referring to the family members.

The following quotes emerged for this subcategory:

"*They only call and pray for me, they are helping me with prayers only." (P1: C)*

"They were calling me every minute to see, to, to, to know the condition of the baby. Truth is, because I needed some items - I have a family member who lives in Pretoria. They were allowed to come and give me what I needed." (P 2: L)

"They do come here. And they always tell me gore (that) No! everything is gonna Just trust in God, believe in God, have faith that your baby is gonna be okay. And when they are at home, they even call me and talk to me and say No! you are gonna be fine, and we are also praying for you and your baby to be okay and come together- Home you and the baby. When they arrive at hospital, we even take a walk. And talk about positive things." (P4: D)

"They give me money to come here to check my baby." (P9: F).

⇒ **Discussions:**

(Bazzan, Milbrath, Soares, Schwartz & Soares 2020:245).

Family support to the participants was a strong emotional enabler and coping mechanism. Support provided by family members is important because it helps in the process of adapting to the child's hospitalisation (Bazzan, Milbrath, Soares, Schwartz & Soares 2019:245) This kind of support made the participants happy as they appreciated the gestures made by their loved ones and assured them that they were not alone.

Not being able to hold their infant whenever they liked, and not being able to visit the infant together with their partner were often mentioned. This study also added that, for parents in general, closeness is not simply about being with their infant physically (being able to hold and take care of their infant), but also about having an autonomous role in taking care of the infant. The study of Meesters, van Dijk, Sampaio, Haverman, Reiss, et al. (2022:110) reflected similar findings.

The family members in this study played a role by financially supporting the parents by paying for their transport to help them travel to the hospital and back home. This was an unnecessary burden for the participants as they could not afford daily travel to the NICU, it also meant that other family members could not visit the hospital due to the financial burden. These findings are affirmed by the findings of Kostenzer, von Rosenstiel-Pulver, Hoffmann, Walsh, Madera, et al. (2021:8) as it concluded about the restrictions mothers experienced in the NICU.

The family support in this present study assisted the participants do deal with the difficult situations that they were faced with daily. The love they received over the phone and sometimes when the family visited proved to be what the participants needed although, some participants did not get visitors as their family members were either far or even located outside the country.

- **Subcategory 2.2.3: External coping: Healthcare support.**

Research literature has demonstrated that one of the most important external resources for coping and adjustment is social support. Social support refers to perceived assistance provided by other persons, such as emotional, informational, and tangible assistance. It is a primary interpersonal resource that has been consistently found to be associated with psychological well-being in times of stress. A study by Hinton et al. (2018:7) reflected on the importance of involving and supporting parents during a critical illness of their babies through engagement and negotiation to form a caring relationship with the staff.

The following quotes revealed that the attitude of the nursing staff made a difference in healthcare support and external coping:

"*Some of the Nurses they are, they are nice. They would tell you nicely, no if you do this the baby will be like this." (P8: K)*

"Yes, I asked, and the Doctor told me the stomach came out so my baby will go to operation so that they can close so that my baby cannot have infection." (P3: D) when she asked the Doctor about the planned treatment of her baby.

Another participant said:
"I am able to ask them to change the nappy for me since I (pauses) maybe sometimes I don't feel comfortable because the baby is sleeping on (pauses) his side. You know? So, I will be asking a sister to help me then they help me." (P5: M)

One participant knew before birth that the expected baby has a gastroschisis. This is what she said regarding healthcare support:

"And then, from there uhm… I woke up in the morning and they tell me that I have given birth to a boy, and then they tell me the condition which I already know about it, and then eh the Doctors were very helpful in giving me the eh the information so, for them to talk to me made it so easy. For me to relax whenever uhm! going to see my child." (P7: D)

One mother also narrated that the nurses told her not to be afraid because the baby is hers, this encouraged her to be more involved in the care of her baby as the nursing staff helped her to overcome her fears. In a study by Rihan et al. (2021:2), it concluded that offering information to parents and engaging them in decision-making regarding their infant, helped in alleviating the anxiety of most parents. The authors further added that parents' trust in the medical staff increased when provided with knowledge about their baby's condition.

Rihan et al. (2021:7) revealed that most parents praised the level of care provided by the health staff and expressed their satisfaction with the medical-staff cooperation, care, education about care, and communication. In this study, some mothers showed great trust and reliance on the health staff and pointed out their support.

3.4.2.3. Category 2.3: Opportunities To Enable Mothers

The last category relating to enablers focused on opportunities that enabled mothers, and three subcategories will be discussed.

- **Subcategory 2.3.1: Opportunities to be with the baby.**

Kim (2020:33) explained the importance of having opportunities for the mother in the NICU to be with her baby. Kim (2020:33) is also of the opinion that maternal opportunities to be with her baby allow the mother to develop a sense of ownership in taking care of their baby.

The following quotes are from the participants:

“Being here in the hospital is good for me because I can visit my baby than to stay at home not seeing how she is doing.” (P1: C)

“We have to stay in one place together. Because I also have to see how baby is recovering day by day.” (P3: D)

“To care for my baby, is when I am around him. The whole, the whole, the whole day, the whole minute, the whole hours.” (P4: D)

“(Sigh) because I love my baby yhoo! (exhales)! I do not want anything about my baby like I want to stay for my baby.” (P6: L)

“I want to see my baby every day.” (P11: N)

⇒ **Discussions:**

Participants in this study raised the importance of being in the same environment as their babies as opposed to being separated. They verbalised that as much as they are not permitted to be with their babies throughout, they appreciated the opportunity to be with their babies despite the limited period. The fact that mothers were admitted in a lodger room, which was not too far from NICU, gave the mothers peace of mind as they were able to visit the NICU regularly.

The above corresponds with the findings of a study by Gómez-Cantarino, García-Valdivieso, Moncunill-Martínez, Yáñez-Araque, & Gurrutxaga (2020:22), who detailed that mothers need to actively participate in daily routines. They need to be heard, understood, and recognised accordingly to the maternal role they play.

- **Subcategory 2.3.2: Opportunities to bond with the baby.**

Maternal involvement in the NICUs plays an important role in facilitating bonding and care interventions between the mother and the infant. Although NICU's primary function is medical assistance for babies, it is also the place where there is the first mother-child encounter and where all the early dynamics of their relationship begin (Trumello et al. 2018:7)**.**

The following are the quotes from the participants:

"They told me that I can touch, play, and talk to my baby so that she hears my voice, to touch her so that she can feel and know that I am her mother." (P1: C)

"Because when they separate me from my baby, it means the baby will never get the sense that I am her mom. So, I must be there for my baby, so that the baby when I touch her can feel me gore (that) I am her mom, (stutter) you see? So that, cause eh, the love that, the love (stutter) the love that a mother has for her baby can also make a baby to, to be strong." (P2: L)

"So, the things that (pause) I need to go to him every day. So, that I can see him akere (isn't it) we don't like, (stutter) I will not take him home. Because he is not stable. So, the thing that I can do is just to go bond, like bond with him, like breastfeeding him, like something like that." (P6: L)

⇒ **Discussions:**

According to Santos and Martins (2017:4076), daily coexistence between mother and baby and seeing the improvement from the treatment caused the mothers in their study to bond with their babies and according to Trumello et al. (2018:2), in turn, helped them to deal with the experience of hospitalisation and having a baby with gastroschisis. Initially, the participants in this study were afraid to interact with their babies because of how their babies appeared, despite having the desire to do so. They reported that the condition of their babies was traumatic, thus they were unable to interact with them. However, things started to change when the nursing staff reassured the mothers about the condition of their babies and also encouraged them to become involved in the neonatal intensive care of their babies.

In a study by Kim (2020:334), the findings reflect on the important role the healthcare team plays in guiding mothers and providing opportunities for the mothers to bond with their babies. The mothers in this study indicated that they felt comfortable after the healthcare team had conversations with them and under the guidance of the nurses, could start to bond with their babies and get involved in the care activities.

Kim (2020:333) expressed that the mothers in their study expressed a strong desire to participate in care in the NICU. The mothers in this study also conveyed that despite the initial separation from their babies, they want to be close to their babies, play with and hold them and allow them to smell them as mothers so they can get used to them being their mothers. In this study, the mothers were allowed to touch, hold and play with their babies because their babies were still being nursed under a radiant warmer and could not yet be carried on their laps. The mothers verbalised that, the feeling of being able to touch their babies made them feel fulfilled, that they were now somehow exercising their role as mothers.

Subcategory 2.3.3: Opportunities to care for the baby

Rihan et al. (2021:2) reported that when parents were encouraged to be engaged in their infant's care, they felt safer, took control of the situation, had more confidence, and felt more connected and related to their infant. Participants of this current study felt that they were exercising their maternal roles when they were allowed to care for their babies in NICU.

The following quotes reflect on the opportunities the mothers experiences which enabled them to care for their babies while in the NICU:

Yes, like holding, like holding a baby, breastfeeding a baby laugh- With the baby: Hold (starter) those tiny hands, when you hold them yhooo (exhale) really feels like No! like this time I really do take care of the baby." (P4: D)

Because I can go and see if he is okay, I see him every day at least I can go and take care of him, change his nappy, make sure that he is okay, Ya. (yes)." (P5: M)

"When we get here, you check your baby's diaper- And then you change them- And then sometimes you find them sleeping like there's nothing you can do (giggle). So, I just sit down and then start, they told us to pump the milk cause now they are not eating, They, so they are preparing us- When the child is supposed to eat, to (starter) to be fed. So that the milk is coming out easily." (P7: D)

That I do? (pause) I went there, I change the nappy, (giggles) I change the nappy; I change even where he is sleeping. I change the linen." (P8: K)

⇒ **Discussions:**

The mothers regarded opportunities to take care of their babies in terms of being able to change their babies' diapers as well as breastfeeding their babies and changing the linen, which made them finally feel that they are, indeed, mothers to their babies.

Lomotey et al. (2020:156), found that breastfeeding and behaviours such as cuddling their babies, talking to them, playing with them, smiling at them, and watching for the response of their babies are opportunities provided to take care of the babies.

Breastfeeding is known to be one of the familiar methods used to connect the mother to her infant, and in this study, the mothers were happy that their babies were able to breastfeed, as it was not the case before surgery. Lomotey et al. (2020: 51) believe that breastfeeding provides an opportunity for mother-baby interaction.

3.4.3 Theme 3: Recommendations of mothers involved in the neonatal intensive care of their babies with gastroschisis

The participants in this study contributed to the formulation of recommendations that will prevent barriers and enable mothers to become involved in the neonatal intensive care of their babies with gastroschisis. Table 3.4: Categories and subcategories for Theme 3: Recommendations of mothers involved in the neonatal intensive care of their babies with gastroschisis.

Table 3.4: Categories and subcategories for theme 3.

THEMES	CATEGORIES	SUBCATEGORIES
3. Recommendations of mothers involved in the neonatal intensive care of their babies with gastroschisis	3.1. Recommendations for the healthcare system	
	3.2. Recommendations to enable mothers	3.2.1. Opportunities to be with the baby
		3.2.2. Opportunities to bond with the Baby
		3.2.3. Opportunities to take care of the Baby

Two categories emerged. For the first category, no subcategories were identified, as opposed to the second category, in which three subcategories were identified. **A discussion will follow (view Chapter 4).**

3.5. Summary

This chapter presented the data analysis and discussion of the findings. A brief description of the demographic data were provided, in addition to a detailed discussion of themes and categories. The results were also embedded in the literature. The next chapter will discuss limitations, recommendations and the conclusion of the research findings.

4. CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

4.1. Introduction

Chapter 3 discussed the findings of the individual semi-structured interviews held with the mothers to explore and describe barriers and enablers they experienced during the neonatal intensive care of their babies with gastroschisis. This chapter discusses the conclusions, recommendations and limitations based on the results of the study.

4.2. Conclusion

This study aimed to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The research question and aim were addressed through a qualitative research design. Individual semi-structured interviews were employed to understand and gain insight into the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The individual semi-structured interviews were transcribed and analysed to identify the following two themes.

4.2.1. Theme 1

Barriers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

The study findings conclude that most participants experienced several barriers when involved in the neonatal intensive care of their babies with gastroschisis. The barriers experienced are as follows: emotional barriers, barriers related to the baby, barriers associated with the health care system, and social barriers.

4.2.1.1. Emotional Barriers

The participants discussed how they felt when told about their babies' diagnoses and their reactions when they saw their babies for the first time in the NICU. The findings revealed that the participants went through fear, shock, and trauma as they were not physically and psychologically prepared for the birth of a baby with congenital abnormalities. The appearance of their babies made it hard for them to interact with these babies. They feared looking at their babies as well as being in the NICU. They also feared losing their babies as they were constantly questioning the babies' survival due to the condition of their babies. The participants also detailed their fears of holding their babies because they thought touching, holding, or doing anything on and for them will be harmful.

Seeing their babies in that critical condition was sad for the participants as it made it difficult for them to look after their babies.

4.2.1.2. Barriers Related To The Baby

The participants detailed that the admission of their babies to the NICU was stressful. They mentioned that the general condition of their babies impacted their lives in a way they never thought was possible. The appearance of their babies was scary to them because they had never heard of or come across gastroschisis, except for one participant who found out during pregnancy. It was also mentioned by the participants that their babies' condition alone was scary, unfortunately, the condition was also accompanied by medical equipment which the babies needed as part of the management of a gastroschisis. The participant indicated that they felt that their babies were going through a lot. They felt pain as their babies were in a poor condition and attached to different types of medical equipment in the NICU which made it difficult for them to hold or touch their babies.

The participants further indicated that the medical equipment was a barrier when it came to getting involved in the neonatal intensive care of their babies because of the noise the machines and how their babies appeared when they were on the machines. The participants mentioned that the machines were helping their babies to stay alive and to cope with their medical condition, however, also contributed to their feelings of uncertainty. The physical environment and other medical equipment such as radiant warmers made the participants feel alienated as they were not familiar with such an environment. They felt that they could not practice their maternal roles as their babies were taken care of by other individuals with the assistance of medical equipment to ensure the recovery of their babies.

4.2.1.3. Healthcare System-Related Barriers

The participants were emotionally challenged as they could not spend enough time with their babies in the NICU because access to NICU was controlled and limited. They suffered separation as a barrier between them and their babies as their babies were in the NICU whereas they were in a different ward. Some were not given accommodation in the hospital, and the participants that were afforded accommodation in the hospitals appreciated the gesture. However, they still were not happy with the limited time they were given to be with their babies in NICU. The participants felt the need to be with their babies throughout their hospitalisation. Not being able to be with their babies as much as they wanted to, affected the participants psychologically.

The participants not accommodated in the hospital endured additional stress from having a sick baby with congenital abnormalities in the NICU, which altered their maternal role, in addition to dealing with the challenges related to the distance. This meant that they had to coordinate their transportation which also added a financial burden. As a result, they were not able to visit the NICU as often as they wished. The physical separation brought by the healthcare system-related barrier affected the participants' parental experiences. The participants who were not accommodated in the hospital mentioned that COVID-19 restrictions contributed to them not being able allowed to lodge in the hospital.

Another barrier that the participants faced was in relation to communication between the participants and healthcare personnel. The participants felt that they were not given enough information related to the condition and progress of their babies. They mentioned that communication between them and the healthcare personnel was little to non-existent. The participants felt that some healthcare personnel were unapproachable and that made communication difficult. They were unable to ask questions about the progress and treatment plan of their babies which resulted in the participants leaving the NICU without knowing how their babies were responding or howtheir progress was. One participant mentioned how the shortage of staff impacted her and her baby's life. She felt that her baby was not getting the care that the baby deserved because the unit was understaffed and had many sick babies.

4.2.1.4. Social Barriers

The participants detailed that being accommodated in the lodger ward of the hospital where their babies were admitted resulted in them being away from their other children and family members back at home because most of them came as transfers from peripheral hospitals. The participants were grateful for being given the opportunity of being able to be with their sick babies in the hospital however, the fact that they were away from home became an additional stress to their already existing stress of having a baby with congenital abnormalities admitted to the NICU. They were often concerned about the well-being of their other children at home as well as their marriages and house chores. The social circumstances experienced by these participants made the mothers to feel as though they have lost their right to independency because they were no longer able to live their lives the way they used to. The mothers could not just leave the hospital to visit their families back home and come back to be with their sick babies.

With reference to all 3 hospital policies, the only time the participants were able to see their families was when some of their family members would visit them in the hospital because they could not visit home themselves. The participants felt that their lives were disrupted due to these social restrictions.

4.2.2. Theme 2

Enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.

4.2.2.1. Emotional Enablers

The participants detailed that, seeing their babies respond to the treatment gave them hope and relief that their babies would recover. Hope and relief made the participants believe that their babies' condition will be corrected and that they will eventually be discharged from the hospital. What also gave other participants hope was when they realised that other mothers had given birth to babies with gastroschisis and witnessing that they had people with whom they could relate eased their stress. The participants also witnessed the recovery of other babies with gastroschisis in the NICU admitted before theirs. These particular babies had just had surgery and responding well to post-surgery treatment.

4.2.2.2. Coping Strategies

The participants detailed that they used different coping strategies to cope with the admission and NICU care of their babies. The internal strategy that the participants believed in was acceptance and prayer because of their religious beliefs. Constant praying offered the participants a sense of calm, hope, and acceptance. They believed that prayer was comforting and that talking to God and telling Him their fears, concerns, and desires helped them to accept the situation which they were faced with. The participants relied on God's mercy and divine intervention for the recovery of their babies. What also assisted the participants to accept the admission and NICU care of their babies, is that they had to familiarise themselves with how NICU functioned and they also noticed the importance of the use of medical equipment on their babies. The recovery of their babies was evident and that made the participants see things differently and develop inner strength.

The external coping strategy that assisted the participants in coping with the situation of having a baby in NICU was family support. The participants made known that the support of their families played a huge role in their lives as their families were taking care of the children that were left at home and they also constantly kept in touch through phone calls checking on how the participants were holding up as well as checking on how their babies were doing in the hospital. Some days the family would visit the participants in the hospital, although the visits were not often because of financial constraints. Most of the participants confirmed that the hospital was outside their province, which made it expensive for their families to visit often, therefore, the participants mentioned that they appreciated the support they were getting from their families, even if it was not physical.

They stated that the family support helped them to adapt to their babies' hospitalisation. The participants not given accommodation in the hospital, mentioned how their families assisted them financially as they had to take public transport to travel to and from the healthcare facility.

Lastly, another coping strategy that the participants detailed, was that of healthcare personnel. The participants made known that some of the healthcare personnel were supportive as they encouraged them to participate in the care of their babies, by telling them not to be afraid of their babies' condition as well as the environment and its medical equipment. The participants mentioned that words of encouragement from the healthcare personnel alleviated their anxiety, and it helped the participants to participate in the care of their babies as they were less afraid.

4.2.2.3. Bonding Opportunities

Opportunities to enable the mothers to be with the baby, to bond with the baby, and care for the baby. The participants detailed the importance of being in the same environment as their babies. They emphasized that separation was neither good for their well-being nor for their babies. They mentioned that the time they were allocated to be with their babies was not enough as they wished to be around their babies as much as they wanted to be. However, they appreciated the limited time given to them. They felt that it was better than not being given a chance at all, and that gave them a sense of peace.

Additionally, the participants detailed how they were given an opportunity of bonding with their babies by the nursing staff, who reassured them regarding their babies' condition. The participants also mentioned how the recovery of their babies made it possible for them to be able to bond and become involved in the neonatal intensive care of their babies.

They mentioned that post-surgery their babies' appearance changed from being scary to being normal which made it easier for the participants to interact with their babies. The interaction was through touching, holding, talking, and breastfeeding their babies which made them feel fulfilled.

Furthermore, the participants were also allowed to get involved in the neonatal intensive care of their babies. The participants detailed that as they were allowed to engage in the care of their babies, they felt that they were finally exercising their maternal roles. They mentioned that being involved in caring for their babies, such as changing diapers and linen, and breastfeeding made them feel like real mothers and they were happy that they were no longer afraid of their babies.

They mentioned that seeing their babies recover made them happy and they just cannot wait for them to be discharged home because they want to be always around their babies.

4.3. Conclusion Regarding Methodology

A qualitative explorative and descriptive design was used to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The researcher used semi-structured individual face-to-face interviews to collect the data. In this study, the conclusion is that the methodology was suitable to collect rich data to answer the research question. Believable descriptions were provided by the participants to develop insight into the barriers and enablers they experienced when involved in the neonatal intensive care of their babies with gastroschisis. Findings were not generalised but recommendations were drafted for the context.

4.4. Recommendations

Recommendations were formulated based on the findings of the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. The researcher made the following recommendations for the Department of Health, Nursing Management, nursing education and training, recommendations to enable mothers and further research.

Recommendations were formulated to enable the mothers' involvement in the neonatal intensive care of their babies with gastroschisis.

4.4.1. Department Of Health

- A conversation can be held with the Department of Health to present the findings regarding emotional barriers and the experiences of the mothers. That can serve as a motivation to request the availability of ultrasonography in antenatal clinics in the peripheral and referral areas. Early diagnosis of gastroschisis will enable the healthcare personnel to start the emotional preparation of the mother for the birth and neonatal intensive care of the baby.
- A request to finance a specialised baby unit for babies with gastroschisis can be discussed with the Department of Health. The planning of a specialised baby unit can be alongside the lodger ward to enable access to the babies to ensure that the mothers are not separated for long from their babies.

4.4.1.1. Recommendations For The Healthcare System

The healthcare system can:

- Develop a strategy for mothers to book antenatal visits as soon as they miss their periods for that month. This will assist in the early detection of gastroschisis, provided the facilities are equipped with ultrasonography.
- Develop a campaign to create awareness to the community regarding the importance of early booking for antenatal care through social media, hospital, and community radios.
- Negotiate for the availability of big screen televisions in the waiting areas such as pharmacies and waiting areas in the unit where information about the benefits of antenatal care and early detection of abnormalities will be broadcasted centrally at a given slot.
- Develop an information leaflet that will inform and guide mothers and their families on how they can be involved in the neonatal intensive care of babies born with gastroschisis.
- Develop a champion staff member who will accompany the mothers from admission to discharge with information and physical closeness to reduce emotional stress.
- Train the mothers who had babies with gastroschisis to become expert mothers who can be contacted when a new baby with gastroschisis is admitted. The trained mother can support and guide new mothers regarding caring the babies who are born with gastroschisis.

4.4.2. Nursing Management

- Nursing management should investigate the possibility to appoint hospital psychologists specifically for the mothers of babies with congenital abnormalities, in this case, gastroschisis. The involvement of the psychologist will provide the mothers with emotional support and coping strategies. The mothers will also learn how to accept the medical condition of their babies, which as a result, will assist in bonding between the mother and the baby, despite the baby having gastroschisis.
- Presenting the findings of the study to Nursing management will start a negotiation process for more lodger facilities or rooms to accommodate the mothers.
- Negotiations with Nursing management will be done to develop a virtual platform for mothers with babies born with gastroschisis and separated for long periods from their families. This recommendation will enable daily virtual conversations with the family.

4.4.3. Nursing Education And Training For Personnel

- Based on the findings of this study, monthly in-service training will be considered for the nursing personnel regarding communication and information sharing when caring for a baby with gastroschisis to ensure that mothers become involved in the care of their babies. This will help to ensure that the nursing personnel is competent enough to communicate and share information with the parents regarding the condition and treatment plan for babies with gastroschisis.
- The researcher will assist the different healthcare facilities to develop a training manual that focuses on the prevention of barriers and the use of enablers to assist the personnel to accompany mothers of babies with gastroschisis to become involved in the neonatal intensive care of their babies.

4.4.4. Recommendations To Enable Mothers

The following recommendations focus on enabling the mothers.

4.4.4.1. Opportunities To Be With The Baby

- The mothers from the peripheral hospital and admitted as referrals to an academic hospital should be transferred with their babies on the same day to prevent bonding disruption.
- The referring hospital should advocate for the transportation of these mothers and discourage the delay of accompaniment.
- The mothers that have gone through difficult delivery should be treated with urgent attention to prevent delayed recovery, this will assist the mothers in being with their babies and will also reduce emotional stress.
- The mothers well enough to be with their babies should be encouraged to be with their babies in the NICU.

4.4.4.2. Opportunities To Bond With The Baby

- The hospital management should advocate for the availability of a psychologist from the first day of admission in the NICU to assist in alleviating feelings of fear, guilt, and judgement from the mothers, which alters the bonding process.

- The nursing personnel looking after the babies with gastroschisis should allow and encourage the mothers to touch, talk, play and even be around their babies, as this will enforce bonding.

- Mothers should be permitted to spend as much time as possible with their babies, provided their presence will not interrupt medical care.
- Nursing and Medical personnel should ensure that the mothers are aware of what treatment their babies are on and how not to interrupt the machines that that babies are attached to, this will assist the mothers to not be fearful during the bonding sessions.

4.4.4.3. Opportunities To Take Care Of The Baby

- The Medical and Nursing personnel should always involve the mothers in the management of their babies in NICU, when mothers feel that they are part of the team and are considered in the decision making they will be encouraged to care for their babies and their stress level will also be reduced.
- The Nursing staff should allow the mothers in caring for their babies from the first visit, despite how sick the babies are unless the mothers are not comfortable doing so
- The mothers who are comfortable and willing to care for their babies despite how sickly they are should be allowed to do so and should be supervised to prevent compromising the baby’s health.
- The mothers should always be kept updated regarding the progress and the recovery of their babies; this will motivate the mothers to be able to care for their babies in the NICU.

4.5. Further Research

Further research is needed to find out what the social impact of separation is on the families at home as well as the coping of mothers with babies born with gastroschisis after discharge.

4.6. Limitations Of The Study

The researcher experienced a low number of participants in the initial institution because some peripheral hospitals were no longer referring their babies with gastroschisis because they were now able to render surgical services with their own a paediatric surgeons. The low number of participants was also due to the restrictions in the initial hospital due to the COVID-19 pandemic. The researcher had to re-apply for ethical consent to conduct the study in another two hospitals, which took several months for approval. This extended the period for data collection longer than expected.

4.7. Reflections Of The Researcher

This study turned out to be demanding on the researcher because, during the pilot study, the researcher was convinced that finding participants for interviews would not be a challenge. However, that was not the case and due to the low number of participants in the specified hospital as documented in the proposal of this study, the researcher had to travel out of the province in search of the participants for data collection.

During the COVID-19 period, the researcher also did not have constant physical meetings with the supervisor and communication was through emails. However, the university assisted by organising fast-track sessions that made provision for supervisors to consult and advise the students. The fast-track sessions were helpful as the researcher managed to have one-on-one meetings with the supervisor who physically guided and explained the processes. Through this study, the researcher has acquired critical skills regarding language, communication skills, and the importance of data interpretation and analysis.

4.8. Disseminations Of The Findings

The following are suggestions for how the researcher will disseminate the findings:

- Publication of the findings in an article format
- Presenting the findings to the hospitals to the management and the NICU, as well as a written report to the Department of Health
- Development of training manuals and information leaflets based on the findings.

4.9. Final Conclusion

The purpose of the study was to explore and describe the barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. This study provided insight into the experiences of mothers of gastroschisis babies admitted to the NICU. Mothers need healthcare personnel who are considerate and have patience in dealing with their emotional reactions. The identified enablers should be used, during early admission to assist mothers of babies with gastroschisis in becoming involved in the neonatal intensive care of their babies.

The researcher approached the study using a qualitative research design and deemed the data collected appropriate and in-depth to meet the objectives of the study.

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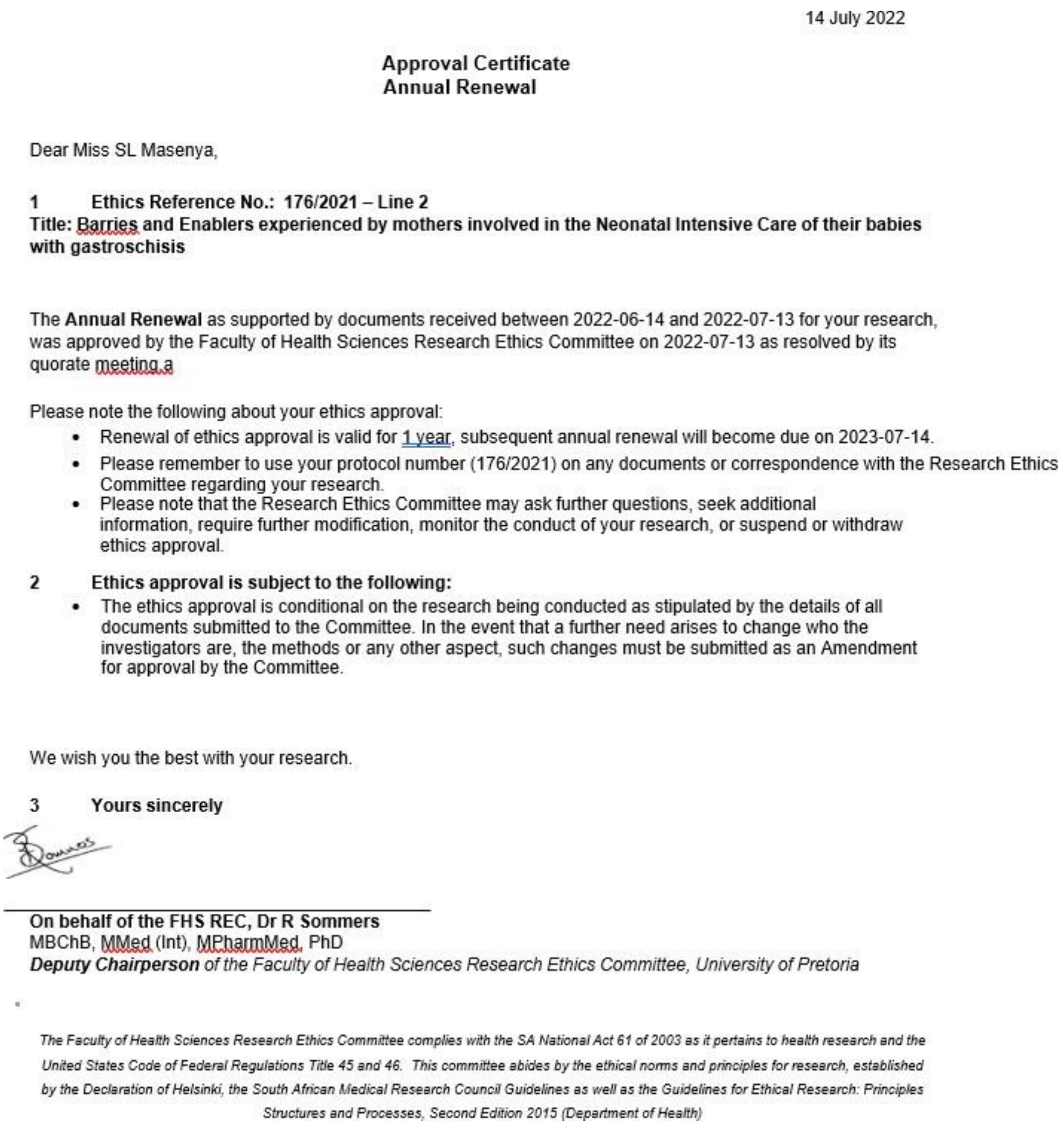
ANNEXURES

ANNEXURE A – LETTER OF APPROVAL ETHICS



14 July 2022

Approval Certificate
Annual Renewal

Dear Miss SL Masenya,

1 Ethics Reference No.: 176/2021 – Line 2
Title: Barries and Enablers experienced by mothers involved in the Neonatal Intensive Care of their babies with gastroschisis

The **Annual Renewal** as supported by documents received between 2022-06-14 and 2022-07-13 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2022-07-13 as resolved by its quorate meeting.a

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2023-07-14.
- Please remember to use your protocol number (176/2021) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

2 Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

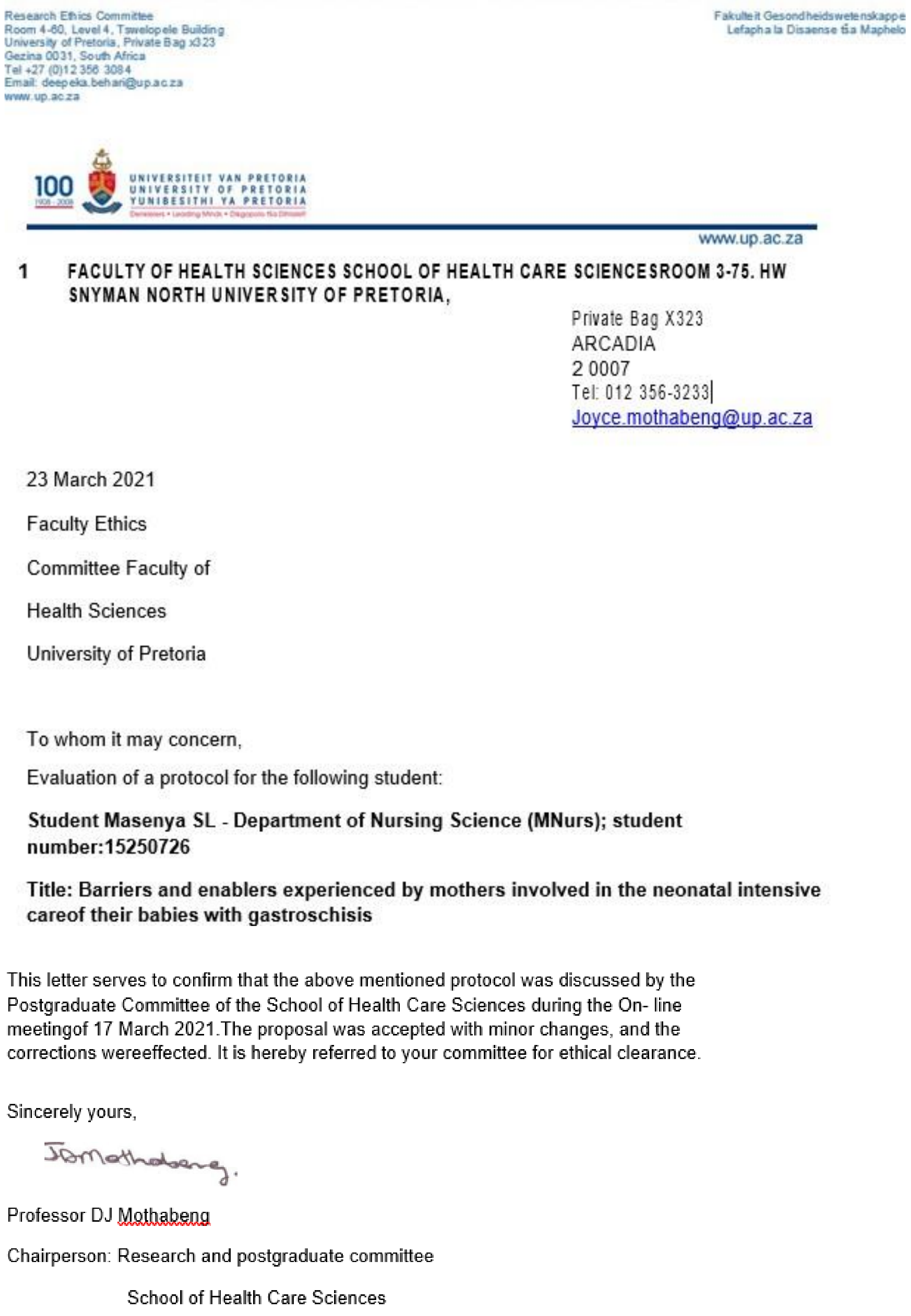
We wish you the best with your research.

3 Yours sincerely

On behalf of the FHS REC, Dr R Sommers
MBChB, MMed (Int), MPharmMed, PhD
***Deputy Chairperson** of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria*

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

ANNEXURE A1 – LETTER OF APPROVAL FROM FACULTY IN HEALTH SCIENCES



Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag x323
Gezina 0031, South Africa
Tel +27 (0)12 356 3084
Email: deepeka.behari@up.ac.za
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Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

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1 FACULTY OF HEALTH SCIENCES SCHOOL OF HEALTH CARE SCIENCESROOM 3-75. HW SNYMAN NORTH UNIVERSITY OF PRETORIA,

Private Bag X323
ARCADIA
2 0007
Tel: 012 356-3233
Joyce.mothabeng@up.ac.za

23 March 2021

Faculty Ethics

Committee Faculty of

Health Sciences

University of Pretoria

To whom it may concern,

Evaluation of a protocol for the following student:

Student Masenya SL - Department of Nursing Science (MNurs); student number:15250726

Title: Barriers and enablers experienced by mothers involved in the neonatal intensive careof their babies with gastroschisis

This letter serves to confirm that the above mentioned protocol was discussed by the Postgraduate Committee of the School of Health Care Sciences during the On- line meetingof 17 March 2021.The proposal was accepted with minor changes, and the corrections wereeffected. It is hereby referred to your committee for ethical clearance.

Sincerely yours,

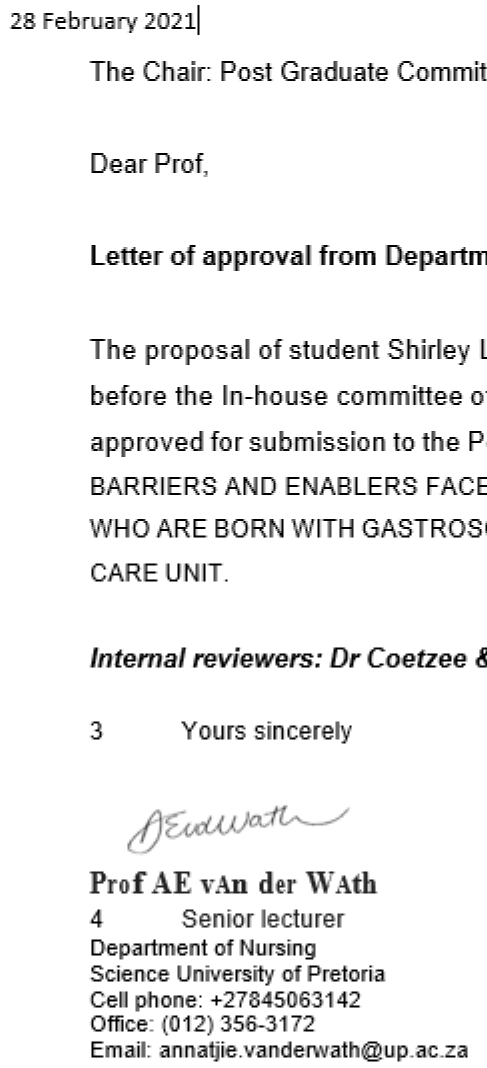
JDMothabeng.

Professor DJ Mothabeng

Chairperson: Research and postgraduate committee

School of Health Care Sciences

ANNEXURE A2 – LETTER OF APPROVAL FROM DEPARTMENT IN-HOUSE COMMITTEE



28 February 2021

The Chair: Post Graduate Committee

Dear Prof,

Letter of approval from Departmental In-house committee

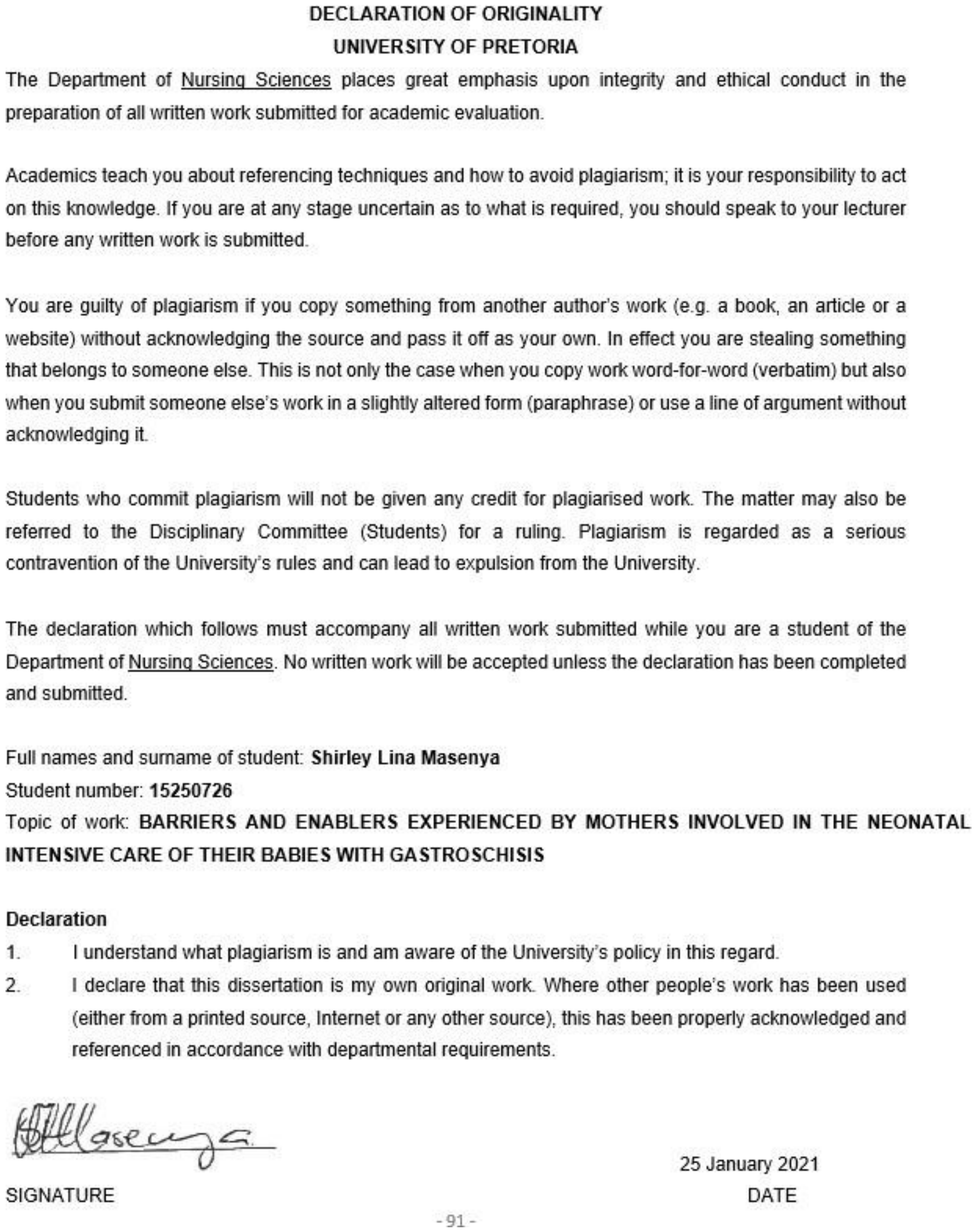
The proposal of student Shirley Lina Masenya, student number: 15250726, served before the In-house committee of the Department of Nursing Science and was approved for submission to the Post Graduate School Committee. The title: BARRIERS AND ENABLERS FACED BY MOTHERS TAKING CARE OF THEIR BABIES WHO ARE BORN WITH GASTROSCHISIS AND ADMITTED IN THE NEONATAL INTENSIVE CARE UNIT.

Internal reviewers: Dr Coetzee & Ms Musie

3 Yours sincerely

Prof AE vAn der WAth
4 Senior lecturer
Department of Nursing
Science University of Pretoria
Cell phone: +27845063142
Office: (012) 356-3172
Email: annatjie.vanderwath@up.ac.za

ANNEXURE B – DECLARATION OF ORIGINALITY



DECLARATION OF ORIGINALITY
UNIVERSITY OF PRETORIA

The Department of Nursing Sciences places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

Academics teach you about referencing techniques and how to avoid plagiarism; it is your responsibility to act on this knowledge. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (e.g. a book, an article or a website) without acknowledging the source and pass it off as your own. In effect you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim) but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department of Nursing Sciences. No written work will be accepted unless the declaration has been completed and submitted.

Full names and surname of student: **Shirley Lina Masenya**
Student number: **15250726**
Topic of work: **BARRIERS AND ENABLERS EXPERIENCED BY MOTHERS INVOLVED IN THE NEONATAL INTENSIVE CARE OF THEIR BABIES WITH GASTROSCHISIS**

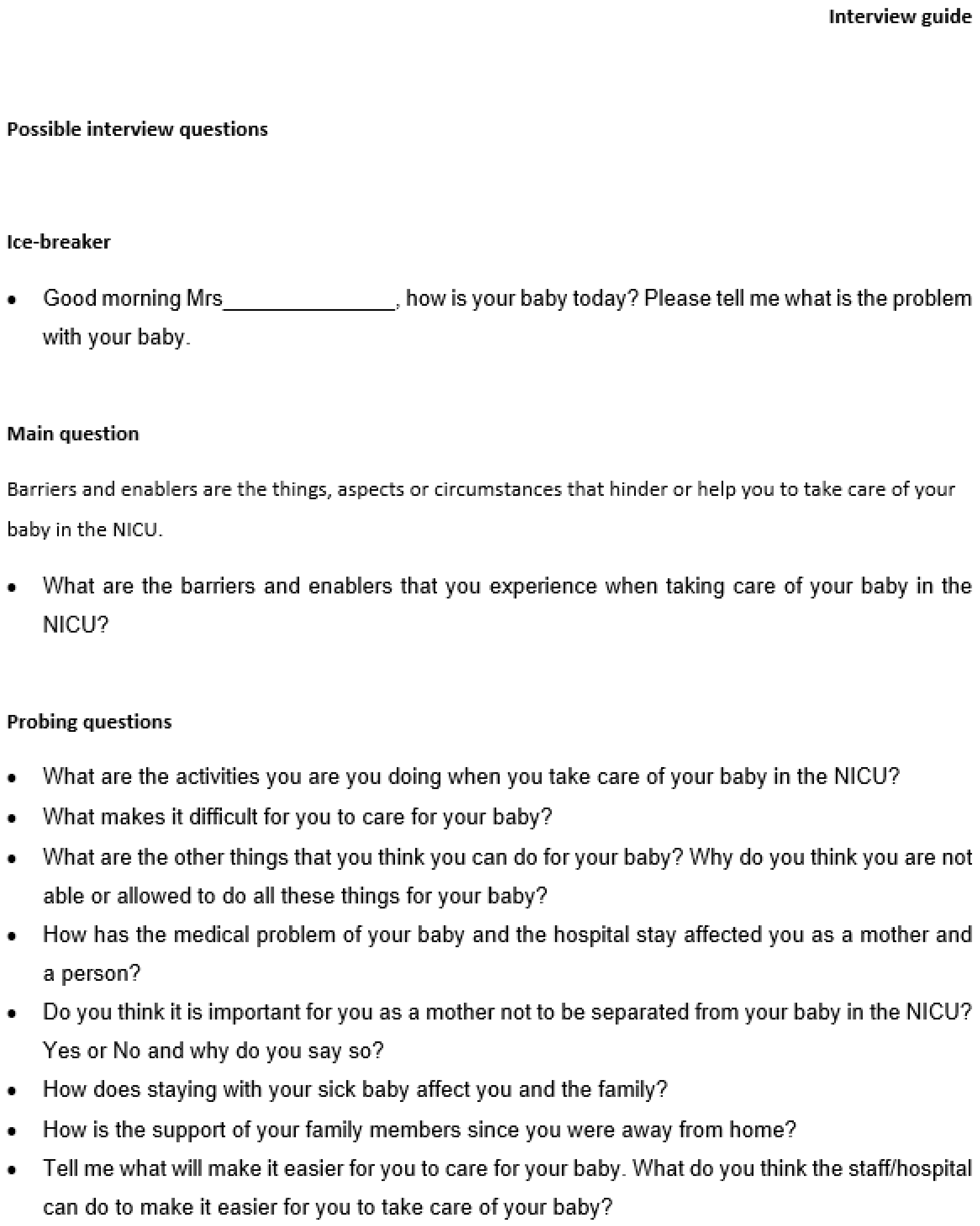
Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this dissertation is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

25 January 2021

SIGNATURE DATE

ANNEXURE C – INTERVIEW GUIDE



Interview guide

Possible interview questions

Ice-breaker

- Good morning Mrs_______________, how is your baby today? Please tell me what is the problem with your baby.

Main question

Barriers and enablers are the things, aspects or circumstances that hinder or help you to take care of your baby in the NICU.

- What are the barriers and enablers that you experience when taking care of your baby in the NICU?

Probing questions

- What are the activities you are you doing when you take care of your baby in the NICU?
- What makes it difficult for you to care for your baby?
- What are the other things that you think you can do for your baby? Why do you think you are not able or allowed to do all these things for your baby?
- How has the medical problem of your baby and the hospital stay affected you as a mother and a person?
- Do you think it is important for you as a mother not to be separated from your baby in the NICU? Yes or No and why do you say so?
- How does staying with your sick baby affect you and the family?
- How is the support of your family members since you were away from home?
- Tell me what will make it easier for you to care for your baby. What do you think the staff/hospital can do to make it easier for you to take care of your baby?

ANNEXURE D – INFORMED CONSENT FORM

PARTICIPANT'S INFORMATION LEAFLET AND INFORMED CONSENT FORM: A NON-INTERVENTION STUDY

STUDY TITLE: BARRIERS AND ENABLERS EXPERIENCED BY MOTHERS INVOLVED IN THE NEONATAL INTENSIVE CARE OF THEIR BABIES WITH GASTROSCHISIS

Principal Investigator: Ms SL Masenya
Institution: University of Pretoria

TELEPHONE NUMBER(S):
Cellular number: 0724514243
Tell number office hours: 0123195793

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Date	Month	Year

Time:

Dear .... date of consent procedure …..... /…......./….......

1) INTRODUCTION

This serves as a formal invitation inviting you to participate in a research study titled**: Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis**. The purpose of this form is to make you fully aware that you understand what the study entails and that you have a choice to participate or not to participate. Please be informed that before taking part in this study you understand what your participation involves as well as the absence of risks and benefits of the study. Your participation is voluntarily therefore, should you wish to withdraw from this study after giving consent please feel free to do so The research study will be conducted in the form of scheduled individual interview sessions and the researcher needs to clarify any misunderstanding before agreeing to take part in the study. If you have any question, you are more than welcome to ask the researcher.

2) AIM AND OBJECTIVE OF THIS STUDY

In this study the researcher will explore and describe the barriers and enablers experienced by the mothers involved in the neonatal intensive care of their babies with gastroschisis. This will allow the researcher to learn more about the barriers and enablers experienced by the mothers in caring for their babies with gastroschisis. The information and especially the data regarding enablers will be useful and shared with the staff and management in helping mothers to overcome barriers they experienced when they are involved in the neonatal intensive care of their babies with gastroschisis.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

In this study the researcher will need to ask questions about barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis. As a mother it will be required of you to answer questions regarding the barriers and enablers you experience during the daily neonatal intensive care contact and activities you do for your baby. The researcher will record the voice of the mothers by using an audiotape to record the conversation in order to be able to listen to it at later stage and the use of audio tape requires the mothers' permission. Verbal and written consent indicating the voluntary participation will be obtained. The consent will be informing the mothers about the purpose of the study before the commencement of the interview. The mothers will be informed that they can withdraw from the study any time should the need arise. The interviews will be carried out in a room where only the researcher and the participant will be present.

4) RISK AND DISCOMFORT INVOLVED.

The researcher will ensure that there's no risk involved to the mothers participating in the study. An interview will last approximately for 30 to 45 minutes. The means of communication during the interview between the researcher and the mothers will be verbal and written communication. There will be no invasive procedures or tests involved and in case of any emotional trauma experienced, the participant will be referred to hospital psychologist or social worker for intervention.

5) POSSIBLE BENEFITS OF THIS STUDY.

The mothers will benefit from this study through the development of a strategy to help them to overcome barriers they experienced when involved in the neonatal intensive care of their babies with gastroschisis. The mothers will able to perform their maternal role in NICU such as changing of diapers, bathing and feeding their babies without any fears and build a bonding relationship with their babies. The results will also benefit the babies as their mothers would develop a positive attitude and an understanding towards their hospitalisation. The results of this study will also be beneficial to the hospital with regards to nursing and medical staff as they would learned what the barriers and enablers are and how to overcome these barriers to actively involving mothers in the treatment plans and general care of their sick babies through.

6) HAS THE STUDY RECEIVED ETHICAL APPROVAL

The researcher received approval from the Ethics Committee of the University of Pretoria, the ethical committee of the institution where the study will be conducted and approval from the Department of Health. The research study will be guided by Declaration of Helsinki guiding the investigator on research procedure involving Human Subjects. Copies will be made available from the investigator on request.

7) INFORMATION

Should the participant have any queries or concerns regarding this study the participant should call: Shirley Masenya at 0724514243

8) CONFIDENTIALITY

In the study the participants will not be called by their real identity. Records and reports on participant's information will be kept away from public access. Final reports for audiences will not display the names of the participants.

9) CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that I have been given information on the objective of the study and the procedures that will take place as well as the risks and discomfort in the study as well as the benefits thereof. Being given information on all aspects of the study and having full understanding of what the study entails from the person asking for my consent, I therefore voluntary agree to participate in the study. I agree to participate freely without being coerced and may withdraw from the study at any time without being affected by it. I also understand and have read about confidentiality of my records and identity during the study. The consent form was signed by me and a copy of the signed consent given to me. I have been given an opportunity to ask questions and with no objection to all information communicated to me.

Participant's name: Date

________________________ _____________

Participant's signature: Date

________________________ _____________

Investigator's name: Date

Shirley Lina Masenya

Investigator's signature: Date

________________________ _____________

Witness: Date

________________________ _____________

CONSENT TO USE VOICE RECORDER

Yes	No	Signature	Date

VERBAL PARTICIPANT INFORMED CONSENT (applicable for participants that can't read or write)

I, the undersigned, Mrs/Ms …………………………………...…… have read and have explained fully to the participant, named .... and/or her relative, I have read and explained the content of this consent form to the participant which indicates the nature and purpose of the study . The explanation I have given is that the participation is voluntary and that the participant is welcome to withdraw from the study should he/she need to. I have also explained to the participant the absence of risks and benefits of the study. The participant has verbalised her understanding of the content included in this form and has agreed to participate in this research study.

Participant's name: Date

________________________ ____________

Participant's signature: Date

________________________ ____________

Investigator's name: Date

Shirley Lina Masenya

Investigator's signature: Date

________________________ ____________

Witness: Date

________________________ ____________

Witness signs that he/she has witnessed the process of informed consent

ANNEXURE E – HOSPITAL PERMISSIONS TO CONDUCT RESEARCH

ANNEXURE D1

PERMISSION TO CONDUCT RESEARCH AT DR GEORGE MUKHARI ACADEMIC HOSPITAL

To: DR LEBETHE
Hospital Manager

From: Ms SL Masenya
E-mail: Shirleymasenya@gmail.com

Re: Permission to conduct research at Dr George Mukhari Academic Hospital

Dear Sir

I am a Nurse Educator at the SG Lourens Nursing Campus, is also clinically trained in Child Nursing Science and previously worked Dr George Mukhari Academic Hospital in Neonatal Intensive Care Unit. I am currently a student at the University of Pretoria, working towards my master's degree in Child Nursing Science. I am kindly requesting permission to conduct a study in the Neonatal Intensive Care Unit with the mothers who gave birth to babies with gastroschisis and admitted in the NICU. The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No.2 of 2000.

The title of the study is**: BARRIERS AND ENABLERS FACED BY MOTHERS WHEN CARING FOR THEIR BABIES WHO ARE BORN WITH GASTROSCHISIS AND ADMITTED IN THE NEONATAL INTENSIVE CARE UNIT**

I intend to publish the findings of the study in a professional journal. The identities of the participants will be protected by assigning each a random number and the name of the Hospital will be kept confidential. I undertake not to proceed with the study until I have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria as well as Gauteng Department of Health.

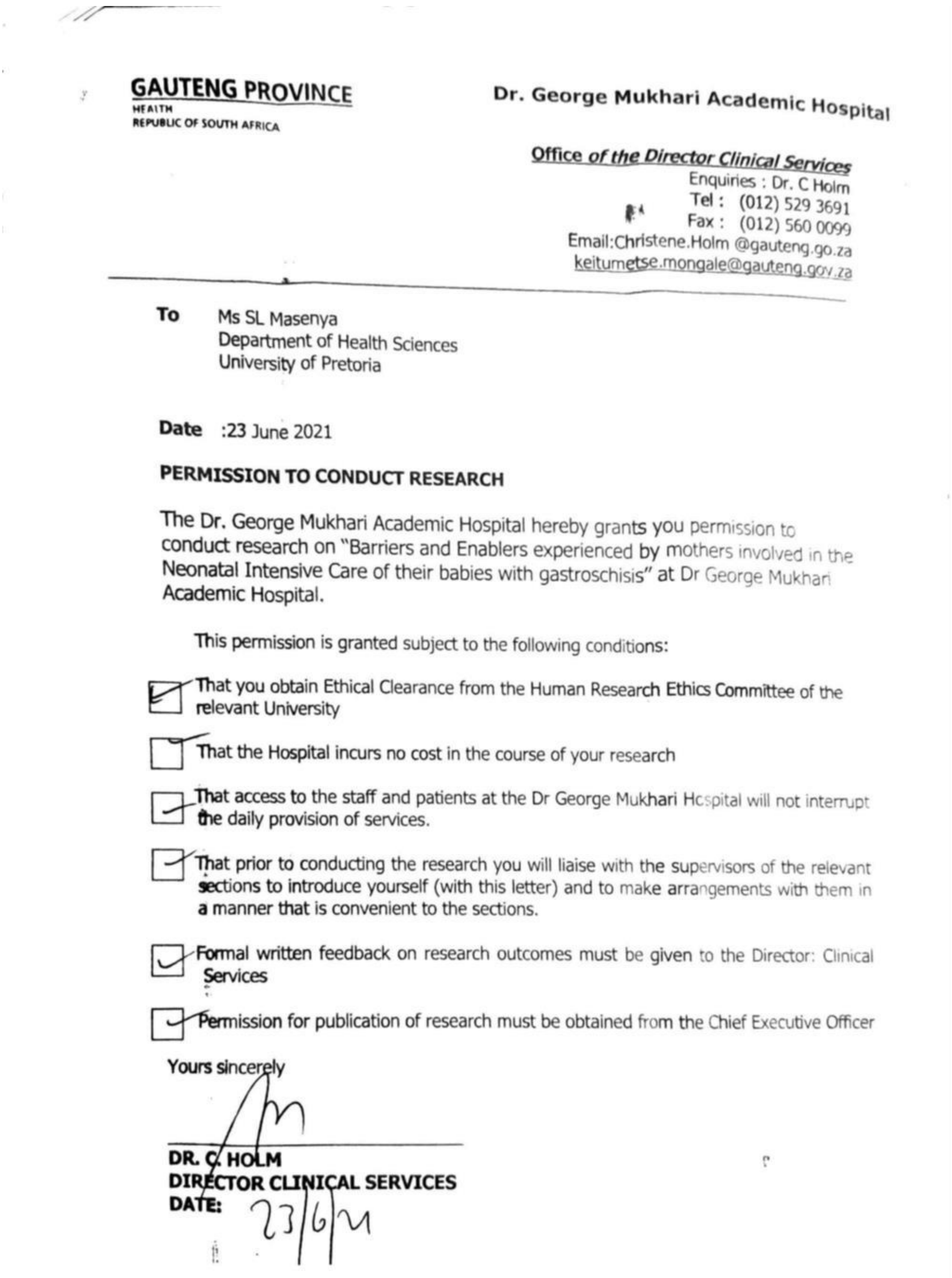
Yours sincerely

Ms SL Masenya
25 January 2021

Permission granted: Yes / No

Mr______________________________(Hospital manager)

Hospital Official Stamp



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Dr. George Mukhari Academic Hospital

Office *of the Director Clinical Services*
Enquiries : Dr. C Holm
Tel : (012) 529 3691
Fax : (012) 560 0099
Email:Christene.Holm @gauteng.go.za
keitumetse.mongale@gauteng.gov.za

To Ms SL Masenya
Department of Health Sciences
University of Pretoria

Date :23 June 2021

PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Academic Hospital hereby grants you permission to conduct research on "Barriers and Enablers experienced by mothers involved in the Neonatal Intensive Care of their babies with gastroschisis" at Dr George Mukhari Academic Hospital.

This permission is granted subject to the following conditions:

☑ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University

☑ That the Hospital incurs no cost in the course of your research

☑ That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services.

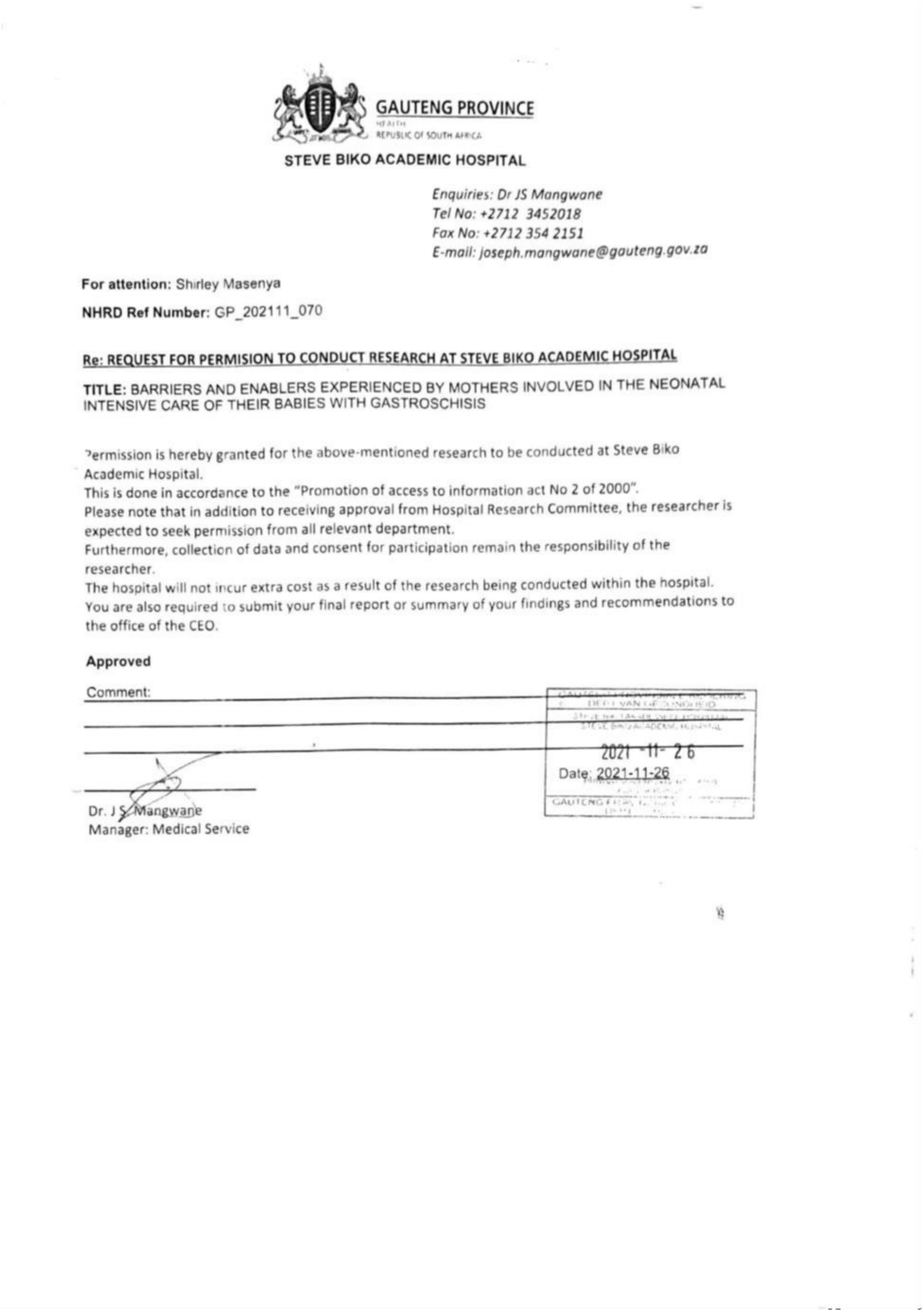
☑ That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.

☑ Formal written feedback on research outcomes must be given to the Director: Clinical Services

☑ Permission for publication of research must be obtained from the Chief Executive Officer

Yours sincerely

DR. C. HOLM
DIRECTOR CLINICAL SERVICES
DATE: 23/6/21



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

STEVE BIKO ACADEMIC HOSPITAL

Enquiries: Dr JS Mangwane
Tel No: +2712 3452018
Fax No: +2712 354 2151
E-mail: joseph.mangwane@gauteng.gov.za

For attention: Shirley Masenya

NHRD Ref Number: GP_202111_070

Re: REQUEST FOR PERMISION TO CONDUCT RESEARCH AT STEVE BIKO ACADEMIC HOSPITAL

TITLE: BARRIERS AND ENABLERS EXPERIENCED BY MOTHERS INVOLVED IN THE NEONATAL INTENSIVE CARE OF THEIR BABIES WITH GASTROSCHISIS

Permission is hereby granted for the above-mentioned research to be conducted at Steve Biko Academic Hospital.
This is done in accordance to the "Promotion of access to information act No 2 of 2000".
Please note that in addition to receiving approval from Hospital Research Committee, the researcher is expected to seek permission from all relevant department.
Furthermore, collection of data and consent for participation remain the responsibility of the researcher.
The hospital will not incur extra cost as a result of the research being conducted within the hospital.
You are also required to submit your final report or summary of your findings and recommendations to the office of the CEO.

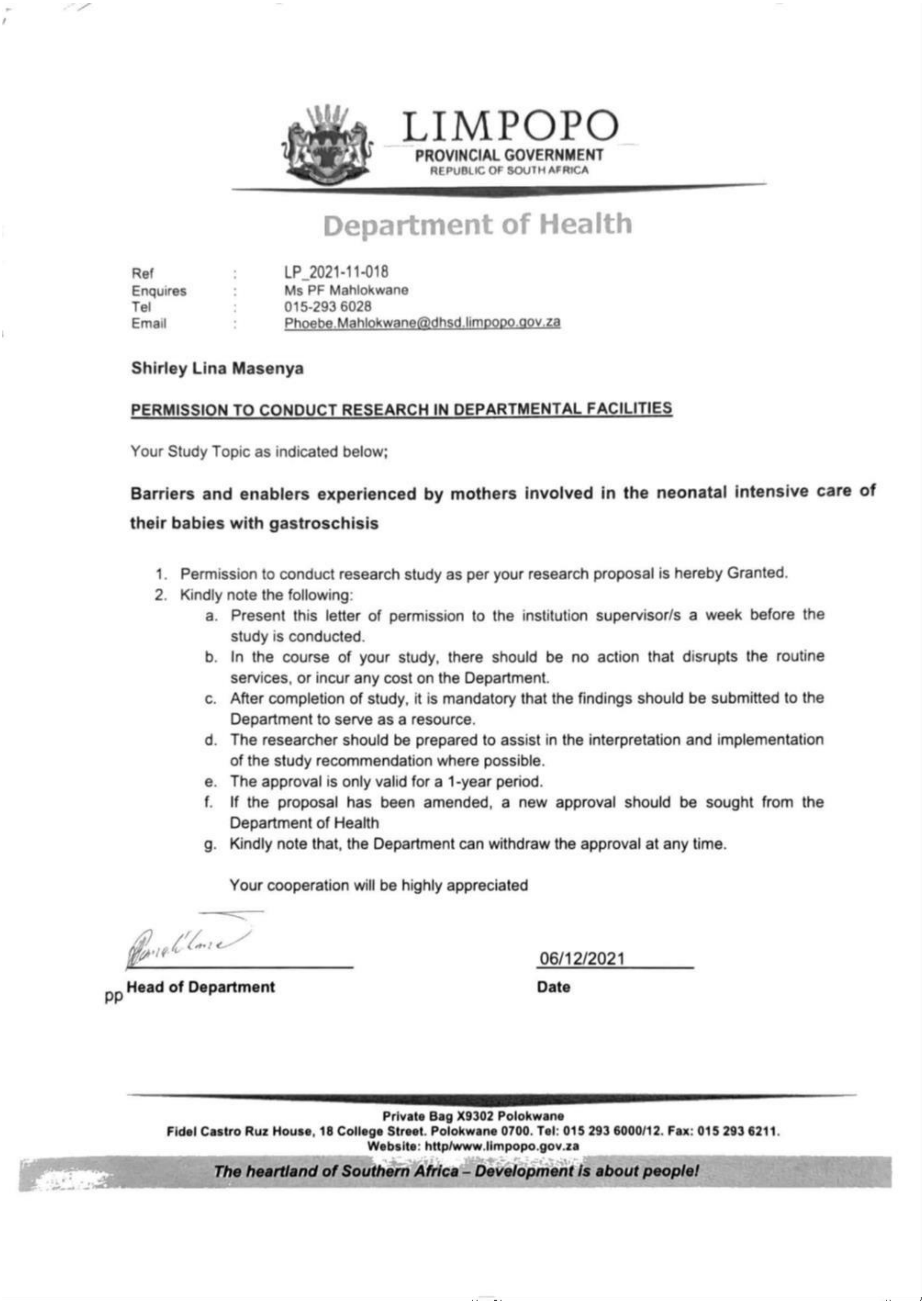
Approved

Comment:

DEPT VAN GESONDHEID
STEVE BIKO ACADEMIC HOSPITAL
2021 -11- 26
GAUTENG

Date: 2021-11-26

Dr. J S Mangwane
Manager: Medical Service



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref	:	LP_2021-11-018
Enquires	:	Ms PF Mahlokwane
Tel	:	015-293 6028
Email	:	Phoebe.Mahlokwane@dhsd.limpopo.gov.za

Shirley Lina Masenya

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
    a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
    b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    e. The approval is only valid for a 1-year period.
    f. If the proposal has been amended, a new approval should be sought from the Department of Health
    g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

06/12/2021

pp **Head of Department** **Date**

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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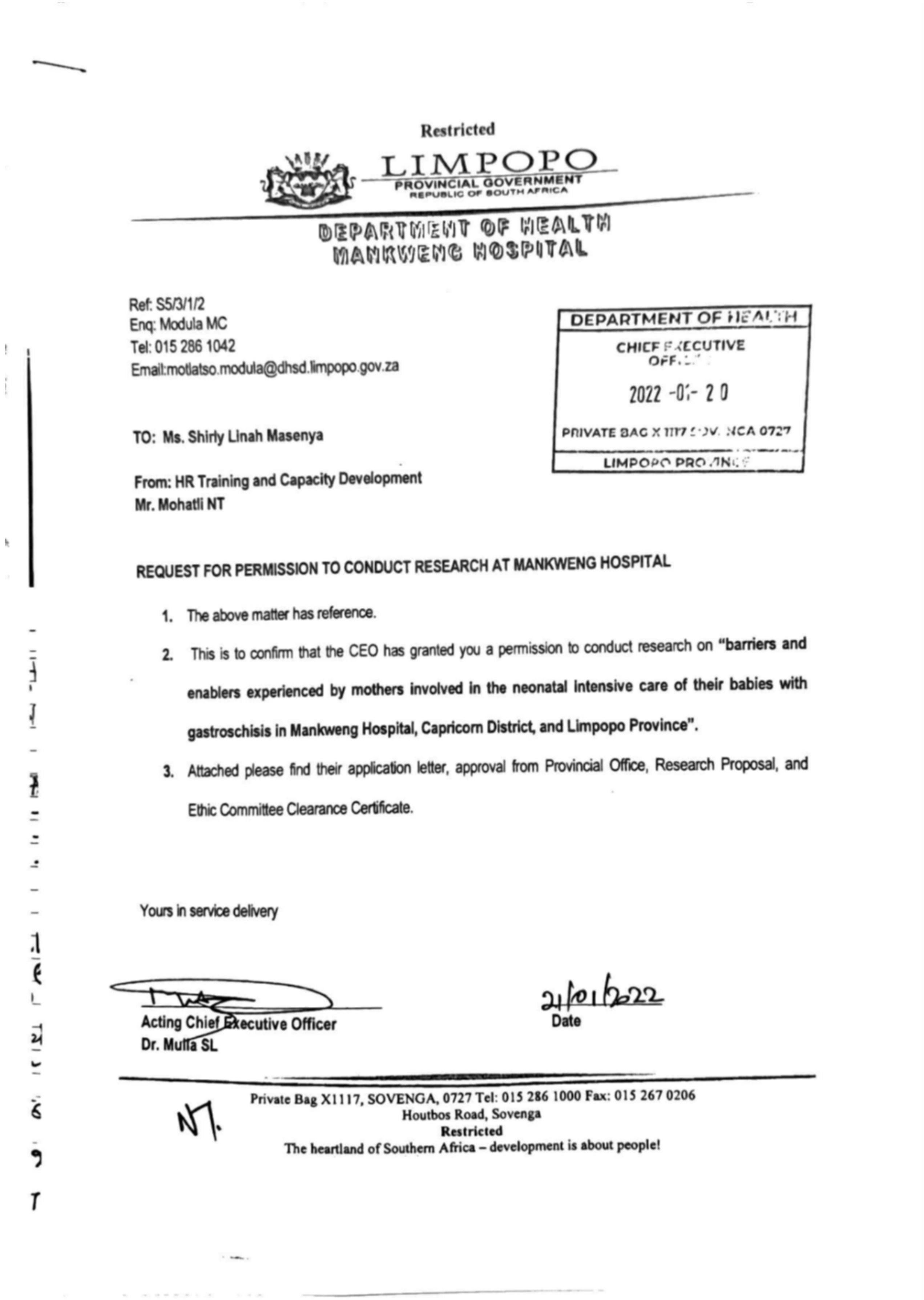

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REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MANKWENG HOSPITAL

Ref: S5/3/1/2
Enq: Modula MC
Tel: 015 286 1042
Email:motlatso.modula@dhsd.limpopo.gov.za

DEPARTMENT OF HEALTH
CHIEF EXECUTIVE OFFICE
2022 -01- 20
PRIVATE BAG X 1117 SOVENGA 0727
LIMPOPO PROVINCE

TO: Ms. Shirly Linah Masenya

From: HR Training and Capacity Development
Mr. Mohatli NT

REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT MANKWENG HOSPITAL

1. The above matter has reference.
2. This is to confirm that the CEO has granted you a permission to conduct research on **"barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis in Mankweng Hospital, Capricorn District, and Limpopo Province".**
3. Attached please find their application letter, approval from Provincial Office, Research Proposal, and Ethic Committee Clearance Certificate.

Yours in service delivery

Acting Chief Executive Officer
Dr. Mulla SL

21/01/2022
Date

NT.

ANNEXURE F – DECLARATION FOR STORAGE OF DATA

Principal Investigator's Declaration for the storage of research data and/or documents

I, Shirley Lina Masenya, the Principal Investigator(s) of the following study: **BARRIERS AND ENABLERS EXPERIENCED BY MOTHERS INVOLVED IN THE NEONATAL INTENSIVE CARE OF THEIR BABIES WITH GASTROSCHISIS** will be storing all the research data and/or documents referring to the above mentioned trial/study at the following residential address:

542 Block BB
Soshanguve
0152

I understand that the storage for the abovementioned data and/or documents must be maintained for a minimum of 15 years from the end of this trial/study.

START DATE OF /STUDY: April 2021 END DATE OF L/STUDY: December 2021

SPECIFIC PERIOD OF DATA STORAGE AMOUNTING TO NO LESS THAN 15 YEARS:
April 2021 until December 2036

Name: SL Masenya

Signature **Date**

Masenya

25 January 2021

ANNEXURE G – DECLARATION OF HELSINKI

All Researchers

Please note that all researchers must from today, sign the attached declaration, when handing in a protocol at the Faculty of Health Sciences Research Ethics Committee - University of Pretoria.

WORLD ASSOCIATION DECLARATION OF HELSINKI
Ethical Principles
For
Medical Research Involving Human Subjects

Adopted by the 18th WMA General Assembly
Helsinki, Finland, June 1964
And amended by the
29th WMA General Assembly, Tokyo, Japan, October 1975
35th WMA General Assembly, Venice, Italy, October 1983
41st WMA General Assembly, Hong Kong, September 1989
48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996
and the
52nd WMA General Assembly, Edinburgh, Scotland, October 2000

A. INTRODUCTION

1. The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principle to provide guidance to physicians and other participants in medical research involving human subjects. Medical research involving human subjects includes research on identifiable human material or identifiable data.

2. It is the duty of the physician to promote and safeguard the health of the people. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.

3. The Declaration of the Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code Medical Ethics declares that "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient."

4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.
5. In medical research on human subjects, considerations related to the wellbeing of the human subject should take precedence over the interests of science and society.

6. The primary purpose of the medical research involving human subjects is to improve prophylactic, diagnostic and therapeutic procedures and the understanding of the aetiology and pathogenesis of disease. Even the best proven prophylactic, diagnostic and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility and quality.

7. In the current medical practice and in medical research, most prophylactic, diagnostic and therapeutic procedures involve risks and burdens.

8. Medical research is subject to ethics standards that promote respect for all human beings and protect their health and rights. Some research population is vulnerable and need special protection. The particular needs of the economically and medically advantaged must be recognised. Special attention is also required for those who cannot give us or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.

9. Research investigators should be aware of the ethical, legal and regulatory requirements for research on human subjects in their own countries as well as applicable international requirements. No national ethical, legal and regulatory requirements should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration.

B. BASIC PRINCIPLES FOR ALL MEDICAL RESEARCH

10. It is the duty of the physician in medical research to protect the life, health, privacy and dignity of the human subject.

11. Medical research involving human subject must conform to the general accepted scientific principles, be based on the thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation.

12. Appropriate caution must be exercised in the conduct of research which may affect the environment, and the welfare of animal used for research must be respected.

13. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol. This protocol should be submitted for consideration, comment, guidance and where appropriate, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. This independent committee should be in conformity with the laws and regulations of the country in which the research experiment is performed. The committee has the right to monitor ongoing trials. The researcher has the obligation to provide monitoring information to the committee, especially any serious

adverse events. The researcher should also submit to the committee, for review, information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest and incentives for subjects.

14. The research protocol should always contain a statement of the ethical considerations involved and should indicate that there is compliance with the principles enunciated in this Declaration.

15. Medical human research involving subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given consent.

16. Every medical research project involving human subject should be preceded by careful assessment of predictable risk and burdens in comparison with foreseeable benefits of the subject or to others. This does not preclude the participation of healthy volunteers in medical research. The design of all studies should be publicly available.

17. Physicians should abstain from engaging in research project involving human subjects unless they are confident that the risk involved have been adequately assessed and can be satisfactorily managed. Physicians should cease any investigations if the risks are found to outweigh the potential benefits or if there is conclusive proof of positive and beneficial results.

18. Medical research involving human subjects should only be conducted if the importance of the objective outweighs the inherent risks and burdens of the subject. This is especially important when the human subjects are healthy volunteers.

C. ICH GUIDELINE FOR GOOD CLINICAL PRACTICE

1. Clinical trials should be conducted in accordance with the ethical principles that have their origin in Declaration of Helsinki, and that are consistent with GCP and the applicable regulatory requirement(s).

2. Before a trial is initiated, foreseeable risk and inconvenience should be outweighed against the anticipated benefit for the individual trial subject and society. A trial should be initiated and continued if the anticipated benefits justify the risk.

3. The rights, safety and well-being of the trial subjects are the most important considerations and should prevail over interest of science and society.

4. The available non-clinical and clinical information on an investigational product should be adequate to support the proposed clinical trials.

5. Clinical trials should be scientifically sound, and described in a clear, detailed protocol.

6. A trial should be conducted in compliance with the protocol that has received prior institutional review board (IRB)/independent ethics committee (IEC) approval/favourable opinion.

7. The medical care given to, and medical decisions made on behalf of, subjects should always be the responsibility of the qualified physician or, when appropriate, of a qualified dentist.

8. Each individual involved in conducting a trial should be qualified by education, training, and experience to perform his or her respective task(s).

9. Freely given informed consent should be obtained from every subject prior to clinical trial participant.

10. All clinical trial information should be recorded, handled and stored in a way that allows its accurate reporting, interpretation and verification.

11. The confidentiality of records that could identify subjects should be protected, respecting the privacy and confidentiality rules in accordance with the applicable regulatory requirement(s).

12. Investigational product should be manufactured, handled, and stored in accordance with applicable good manufacturing practice (GMP). They should be used in accordance with the approved protocol.

13. Systems with procedures that assure the quality of every aspect of the trial should be implemented.

Name	Student Number	Department	Author or acknowledgement and signature
Shirley Lina Masenya	15250726	Nursing Science	

ANNEXURE H – PARTICIPANT 9 FLORIDA – TRANSCRIPT ORGINAL INTERVIEW

Participant 9 Florida

Interviewer: Good morning mother.
Participant: I am fine and you?
Interviewer: Please try to relax and speak and speak louder so, that the recording can record you.
Participant: Yes.
Interviewer: Okay! I am going to start again.
Interviewer: Good morning mother.
Participant: I am good and how are you?
Interviewer: I am okay. My name is Shirley. What is your name?
Participant: My name is Florida.
Interviewer: Okay Florida. I am a Lecturer at Ga-Rankuwa Campus, it is a nursing campus. I am also a student at the University of Pretoria I am conducting a study which is called Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis.
Participant: Okay!
Interviewer: Okay. It's a study that I am doing. I understand that you have given birth to a baby with gastroschisis.
Participant: Yes.
Interviewer: So, I am at the right place, and I am interviewing the right mother.
Interviewer: Am I?
Participant: Yes.
Interviewer: Okay! How is your baby today?
Participant: She is good.
Interviewer: She is good.
Participant: Yes.
Interviewer: What is the problem with your baby?
Interviewer: Did they tell you?
Participant: No.
Interviewer: You don't know why you are here?
Participant: Is for gastroschisis.
Interviewer: Gastroschisis.
Participant: Yes.
Interviewer: Okay!
(silence)
Interviewer: So, eh! You said your name is?
Participant: Florida.
Interviewer: Okay Florida. Florida. This is formal invitation for you to participate in my research study. Like I said my research study title is **Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis**.

Participant: Yes.

Interviewer: Do you understand what this title is about?

Participant: Yes, I understand.

Interviewer: You understand. Can you tell me what gastroschisis is?

Participant: Mmhmm.

Interviewer: In your own understanding. (Clears throat)

Participant: Gastroschisis.

Interviewer: Mm.

Participant: Is a baby intestine out.

Interviewer: Okay!

Participant: Mmhmm (giggle).

Interviewer: That’s all you know.

Participant: Yes.

Interviewer: Okay. Gastroschisis is a birth abnormality that occurs while a woman is still pregnant.

Participant: Mm.

Interviewer: The abdominal wall does not close in normal pregnancy resulting in a baby being born with an opening on the belly.

Interviewer: Do you get this?

Participant: Yes.

Interviewer: Yes, therefore, when the baby is born, the baby Interviewer: will be born with an opening on the abdomen which we know as the belly.

Participant: Yes.

Interviewer: What happened?

Interviewer: Why was your baby born with intestines outside the belly?

Interviewer: It is because there was a failure of the abdominal wall to close during pregnancy which caused the insides of the abdomen which are the intestines, liver, and stomach to be visible outside the baby’s body.

Participant: Okay! All right.

Interviewer: Do you get it?

Participant: I understand.

Interviewer: Yes. It happened while you were still pregnant.

Participant: Yes.

Interviewer: When you are pregnant the baby grows.

Participant: Yes.

Interviewer: The baby goes through developmental stages. So, in your case the baby continues to develop whereas the abdominal wall was not closing.

Participant: Yes.

Interviewer: So, everything that was supposed to be inside, it continued to grow even though the wall of the abdomen did not close. Hence your baby was born with-

(Both speaks) intestines outside the?

Participant: Stomach.

Interviewer: The stomach.

Interviewer: Gastroschisis is an abnormality that is usually seen in new-born babies who are born before the completed nine months of pregnancy.

Interviewer: How far were you in your pregnancy?

Participant: Mmhmm!

Interviewer: How many months were you?

Participant: Nine.

Interviewer: Were you nine months?

Participant: Yes.

Interviewer: Forty weeks full?

Participant: Yes.

Interviewer: Did you complete the whole nine months?

Participant: Yes.

Interviewer: Are you sure?

Participant: Yes, I am sure.

Interviewer: Okay. So, this abnormality usually occurs in the mothers who did not complete nine months of pregnancy. But like you said you completed the nine months.

Participant: Yes.

Interviewer: All right. So, this babies who are born with gastroschisis after delivery they are immediately be transferred and admitted in a Neonatal Intensive Care Unit for specialised care.

Participant: Yes.

Interviewer: Where was your baby born?

Participant: Here in Steve Biko.

Interviewer: In Steve Biko.

Participant: Yes.

Interviewer: Okay! Where are you from?

Participant: Tembisa.

Interviewer: You are from Tembisa.

Participant: Yes.

Interviewer: So, you were transferred from Tembisa to come give birth here in Steve Biko?

Participant: Yes.

Interviewer: Do you know why?

Participant: Mmhmm! They tell me that baby mm... intestines are out-

Interviewer: Before you gave birth?

Participant: Side the stomach. Yes.

Interviewer: So, they could see before the baby was born-

Participant: Yes.

Interviewer: That your baby has gastroschisis.

Participant: Yes.

Interviewer: And then they transferred you-

Participant: Steve Biko.

Interviewer: To Steve Biko.

Participant: (Nod)

Interviewer: (Clicks tongue) So, why am I here and what am I aiming to get from you?

Interviewer: In this study I am aiming-

Participant: (Nod)

Interviewer: To find out what is making it difficult for you to care for your baby and what can be done to help you care for your baby.

Interviewer: The purpose of this form that I am having with me, is to make you fully aware that you understand what the study is about.

Participant: (Nod)

Interviewer: Remember I did say before we started this interview that you have a choice to participate or not to participate. You are not forced.

Participant: Yes.

Interviewer: You have given me your consent to say it is okay we can continue with this study.

Participant: You are free to withdraw-

Participant: Yes.

Interviewer: If you feel that No! I cannot continue with this then it's okay I will understand and respect your decision.

Interviewer: Yes. The aim and objective of this study: I want to explore and describe the barriers and enablers that you are experiencing when involved in the care of your baby with gastroschisis.

Participant: (Nod)

Interviewer: Why is this important?

Participant: This is important because it will help me to learn more about the barriers and enablers you as a mother is experiencing when taking care of your baby.

Participant: Yes.

Interviewer: Yes. This information and especially the data regarding the enablers will be useful and I will share it with the staff and management in helping you to overcome barriers that you are experiencing when involved in the neonatal intensive care of your baby with gastroschisis.

Participant: Yes.

Interviewer: This will be the benefits. Remember we talked about the benefits?

Participant: Yes.

Like how this will benefit you.

Participant: Yes.

Interviewer: This will benefit you and other mothers as a strategy would be developed to help you overcome the barriers you experience when involved in the neonatal care of your baby with gastroschisis.

Interviewer: You will be able to perform your maternal role when taking care of this baby who has gastroschisis, who is your baby.

Participant: Yes.

Interviewer: The results will also benefit your baby because you as a mother would develop a positive attitude and an understanding towards your baby's hospitalisation.

Participant: Yes.

Interviewer: Yes. The results also will be beneficial to the hospital regarding nursing and medical staff as they would have learned what the barriers and enablers are and how to overcome these barriers to actively involve the mothers in the treatment plans and general care of their sick babies. So, this will help you. Other mothers and the hospital as whole-

Participant: Yes.

Interviewer: Because you would have learned how to overcome the barriers.

Participant: Yes.

Interviewer: Ne (Right)!

Interviewer: And then the staff will know what to do to help you care for this baby who has gastroschisis.

Participant: Yes.

Interviewer: They will make you part of their nursing care treatment.

Interviewer: Ne (Right)

Participant: Okay.

Interviewer: Yes, and the procedure that I followed; remember I did tell you that my study received Ethical approval.

Participant: Yes.

Interviewer: My study also received permission from the hospital's CEO, the sisters in this unit, they have given me permission to conduct this study, and you as a mother have also given me permission and you have also signed a consent that I record you. You are allowing me to verbally interview you.

Participant: Yes.

Interviewer: Is that so?

Participant: Yes.

Interviewer: Yes.

Interviewer: What about the risks involved or any discomfort?

Interviewer: I will not put you at any risk, like I said our interview will take close to 30 to 45 minutes-

Participant: Mmhmm.

Interviewer: And uhm! (Clears throat) There will be no invasive procedures or tests involved and in the were you experience emotional trauma experienced, you will be referred to hospital psychologist or social worker for intervention.

Participant: Okay.

Interviewer: Yes. I have my number here; you can use this number to contact me if you have any concerns or if you need any clarity.

Participant: Okay.

Interviewer: Okay!

Interviewer: What about confidentiality? In this study, you will not be called by your real identity. Records and reports on your information will be kept away from public access. The final reports for audience will not display your name. Meaning the results of this study, will be anonymous. Your name will not be known. You will be referred to as a mother of and not by your real name.

Participant: Okay.

Interviewer: Thank you for giving a consent to continue with this study. Now we are ready to start, and I thank you for this opportunity I really appreciate it.

Participant: Okay.

Interviewer: So, now we are going to start with our questions.

Interviewer: Remember to feel free.

Participant: Yes.

Interviewer: Feel free, you are not in an exam room.

Participant: (Giggle) Yes.

Interviewer: Your feelings are your feelings. Okay!

Participant: Yes.

Interviewer: Okay. Barriers and enablers are the things, aspects or circumstances that hinder or help you to take care of your baby in the Neonatal ICU.

Participant: Mm.

Interviewer: What are the barriers that you as a mother is experiencing when taking care of your baby in this ward?

Participant: Mmhmm!

Interviewer: Do you understand the question?

Participant: No.

Interviewer: You don’t.

Participant: Yes.

Interviewer: Remember what I said barriers are?

(Silence)

Interviewer: Do you remember?

Participant: Yes.

Interviewer: What did I say barriers are?

Participant: (Pause) You said the barriers uhm! (Exhale and giggle)

Interviewer: Please speak louder.

Participant: Mmhmm.

Interviewer: Can you hear how loud I am speaking?

Participant: Yes.

Interviewer: I also want to be able to hear you, and for the recording to be able to record you.

Participant: Okay.

Interviewer: Remember I said the barriers are the things that are stopping you from doing what you want to do for your baby.

Participant: Mmhmm.

Interviewer: When was your baby born?

Participant: Mmhmm! I gave birth.

Interviewer: When?

Interviewer: Date?

Participant: Mmhmm, 2 February, 10 February.

Interviewer: 10 February.

Participant: Yes.

Interviewer: Okay! When did you start taking care of your baby while in the hospital?

Participant: Mmhmm, since from 10 February.

Interviewer: Since from 10th February?

Participant: Yes, until now.

Interviewer: Until now.

Participant: Yes.

Interviewer: Were you able to do the things that you as a mother wanted to do for your baby?

Participant: No.

Interviewer: No?

Participant: Yes.

Interviewer: What were you unable to do?

Participant: What?

Interviewer: What was it difficult for you to do for your baby?

Participant: Mmhmm!

Interviewer: Remember you said you were not able to care of your baby as you would want to as a mother. Now I am asking you, what was difficult for you to care for your baby?

Participant: Nothing.

Interviewer: Nothing?

Participant: Yes.

Interviewer: Okay! So, tell me what were you doing for your baby?

(Silence)

Interviewer: What are the activities that you were doing when you were taking care of your baby?

Participant: (Pause) Nothing.

Interviewer: What were you doing for your baby, you said you were taking care pf your baby from the 10th of February until now?

Participant: Yes.

Interviewer: What is it that you do?

Participant: I breastfeed

Interviewer: You breastfeed.

Participant: Yes.

Participant: I bath.

Interviewer: You bath.

Participant: Yes, I am changing nappy.

Interviewer: You change nappy.

Participant: Yes.

(Silence)

Interviewer: What else do you do?

Interviewer: (Coughing) excuse me.

Participant: mm.

Interviewer: (Coughs) What else do you do for your baby?

Participant: Mmhmm! Nothing.

Interviewer: So, is it easy for you to take care of your baby in this hospital?

Participant: Uhm! (Shaking head)

Interviewer: It is not easy?

Participant: It is easy.

Interviewer: It's easy?

Participant: (Giggle)

Interviewer: What makes it easy?

Participant: Mmhmm! (pause)

Interviewer: What makes it easy for you to take care of your baby? Remember to be free.

Participant: Yes.

Interviewer: Mm.

Interviewer: What is helping you to take care of your baby?

Participant: Is Doctors.

Interviewer: The Doctors.

Participant: Yes.

Interviewer: What are they doing to help you? (Clears throat)

Participant: They give him medication.

Interviewer: Mmhmm.

Participant: And (pause) help!

Interviewer: What else do they do?

Participant: Mmhmm! And when I am not here, they change her nappy.

Interviewer: Mmhmm.

Participant: Bathing her.

Interviewer: Mm.

Participant: Yes.

Interviewer: Okay!

Interviewer: What is it that you as a mother you wish to do for your baby?

Participant: (Pause) Mmhmm! Nothing for now.

Interviewer: Nothing?

Participant: Yes.

Interviewer: Okay! So, you said you are breastfeeding your baby.

Participant: Mm.

Interviewer: Right?

Participant: Yes.

Interviewer: When did you start breastfeeding?

Participant: Mmhmm!

Interviewer: Remember you said your baby was born on the 10th of February.

Participant: Yes.

Interviewer: When did your baby start breastfeeding?

Participant: I can't remember.

Interviewer: Was it soon after birth or was it later?

Participant: Later.

Interviewer: Later.

Participant: Yes.

Interviewer: So, in the beginning what was your baby eating?

Participant: They give him kuthiwa yini? (What is it called) wanikezwa ngemithambo. (She was fed through veins).

Interviewer: They were feeding her through veins.

Participant: Yes.

Interviewer: You were not breastfeeding at that time?

Participant: No.

Interviewer: Why?

Participant: Mmhmm! They said intestines out so, angikwazi kuthi ngimcelisi (I could not breastfeed her).

Interviewer: Okay. The intestines were out so you couldn't breastfeed-

Participant: Yes.

Interviewer: The baby.

Participant: Yes.

Interviewer: Did that not make it difficult for you to care for your baby?

Participant: Mmhmm! No.

Interviewer: Was it not difficult for you?

Participant: It was difficult.

Interviewer: What was difficult?

Participant: (Giggle) mmhmm!

Interviewer: Talk to me.

(Silence)

Interviewer: What was difficult for you to care for your baby when the intestines were out?

Participant: Mmhmm! Nothing.

Interviewer: Nothing.

Participant: Yes.

Interviewer: So, you seeing your baby with intestines outside, it was okay with you?

Participant: No.

Interviewer: It wasn't okay with you.

Participant: No.

Interviewer: What was it like?

Participant: (Exhale) I don't know.

Interviewer: Sorry!

Participant: I don't know.

Interviewer: No! mother. You cannot say you don't know.

Interviewer: Do you know what difficult means?

(Silence)

Interviewer: It means something that is hard-

Participant: Yes.

Interviewer: To do.

Participant: Yes.

Interviewer: Was it hard for you when you saw your baby with intestines outside?

Participant: For carrying her.

Interviewer: For carrying her.

Participant: Yes.

Interviewer: Like picking the baby-

Participant: Yes.

Interviewer: Up.

Participant: Yes.

Interviewer: So, you could not pick her up because?

Participant: Mmhmm! I was scared of the intestines.

Interviewer: You were scared of the intestines.

Participant: Yes.

Interviewer: And what else were you scared of?

Participant: The intestines only.

Interviewer: Okay! So, you are saying you were not able to pick up the baby because the intestines were out.

Participant: Yes.

Interviewer: What else did you want to do for your baby that you were not able to do because of the intestines?

Participant: Mmhmm! Nothing.

Interviewer: Nothing.

Participant: Yes.

Interviewer: Okay!

(Silence)

Interviewer: The medical problem of your baby and the hospital stay, how has it affected you as a mother and as a person?

Participant: Uhm!

Interviewer: Your baby is in the hospital.

Participant: Yes.

Interviewer: You as a mother, how does it make you feel?

Participant: I am feeling good.

Interviewer: You are feeling good?

Yes.

Interviewer: That your baby is in the hospital?

Participant: No.

Interviewer: How are you feeling?

I am stressed.

Interviewer: You are stressed.

Participant: Yes.

Interviewer: What stresses you?

Participant: Mmhmm!

Interviewer: Why are you stressed?

Participant: Because I see her maybe after two weeks.

Interviewer: Mmhmm.

Participant: Yes.

Interviewer: So, you do not stay in the hospital?

Participant: No.

Interviewer: You go home?

Participant: Yes.

Interviewer: Okay!

Participant: (Sobs)

Interviewer: So, what do you think can be done to help you?

Participant: (Sobs)

Interviewer: Because your baby is in the hospital, (hands over a tissue to the mother) and you don't get to see you baby as much as you want to. What do you think the hospital can do for you?

Participant: To change my baby to another hospital.

Interviewer: To change your baby to another hospital.

Participant: Yes.

Interviewer: Okay! Remember when I was telling you about gastroschisis: I said the babies are transferred to a specialised unit.

Participant: Yes.

Interviewer: The baby was transferred here because they know that, in this hospital the baby will get all the care that she needs.

Participant: Okay.

Interviewer: Yes, do you understand?

Participant: Yes.

Interviewer: Okay! (Clears throat)

Interviewer: Do you think it is important for you as a mother not to be separated from your baby?

Participant: What?

Interviewer: Is it important for you as a mother not to be separated from your baby?

Participant: Uhm!

Interviewer: Do you think, like now you are saying you live in Tembisa, and your baby is here in Steve Biko. This means you are separated.

Participant: Yes.

Interviewer: Do you think it is good?

Participant: No.

Interviewer: Why is it not good?

Participant: (Pause) Because I don't know my baby. angazi kuthi udla ini. (I don't know if she is being fed)

Interviewer: You don't what your baby is eating?

Participant: Yes, angazi kuthi ulala kanjani (I don't know how she sleeps) (sobs).

Interviewer: You don't know how the baby sleeps.

Participant: Yes.

Interviewer: How many times do you get to see your baby?

Participant: Many times.

Interviewer: Mmhmm. How many times?

Participant: Mon-

Interviewer: Do you come to see your baby?

Participant: Monday and Friday.

Interviewer: Monday and Friday.

Participant: Yes.

Interviewer: So, this is making you to feel?

Participant: Stressed.

Interviewer: It is making you to feel stressed.

Participant: (Nods and sobs).

Interviewer: Okay!

Interviewer: Is there any support that you are getting from your family?

Participant: Yes.

Interviewer: How are they supporting you?

Participant: They give me money to come here to check my baby.

Interviewer: Okay! They give you money to come here and check on your baby.

Participant: (Sniffles) Yes.

Interviewer: And then how are they feeling, how is this affecting them?

Interviewer: You said your sick baby and being away from your baby is giving you stress, how is your family?

Participant: Nabo ba (They are also) stressed.

Interviewer: They are also stressed.

Participant: Yes.

Interviewer: Okay eh! Mama tell me, what do you think will help to take care of your baby?

Participant: What do you think the hospital can do, to make it easier for you to care for your baby? Mmhmm!

Interviewer: What do you think they can do?

(Silence)

Interviewer: Remember you said if they can transfer you to another hospital?

Participant: Yes.

Interviewer: So, what else do you think they can do?

Participant: Mm! nothing.

Interviewer: Tell me.

Participant: (Sniffles)

Interviewer: What do you think they can do to help you?

Participant: (Pause) to come and sit here.

Interviewer: To allow you to sit here.

Participant: Yes.

Interviewer: Okay! Sitting here, what do you mean? Explain.

(Silence)

Interviewer: Please explain to me what you mean when you say to sit here.

Participant: kuthi ngi be eduze no mtwana (So I can be close to the baby).

Interviewer: Mmhmm.

Participant: Ngi khone ku mcelisa (So I can breastfeed her) the whole day.

Interviewer: Okay! So, you want-

Participant: Ngi bone kuthi ulele kanjani (So I can see how she sleeps) (sobs)

Interviewer: Okay! So, you want to be able to stay with your baby so that you can be able to see how the baby is doing-

Participant: Mm.

Interviewer: How the baby, how the baby slept so that you can be able to breastfeed your baby as well.

Participant: Yes.

Interviewer: That is important to you?

Participant: Yes.

Interviewer: Okay!

Participant: (Sniffles)

Interviewer: Mm! am going to try and go back to see and summarise what we have spoken about.

Interviewer: Correct me if I am wrong.

Okay! When I asked you about the activities that you do for your baby, you said you are Interviewer: breastfeeding your baby-

Participant: Yes.

Interviewer: You are bathing your baby; you are changing the nappy.

Participant: Yes.

Interviewer: What else?

Participant: (Shakes head).

Interviewer: Okay! And then when I asked you about the difficulties you said what was difficult was when your baby's intestines were outside.

Participant: Yes.

Interviewer: You said the baby's intestines were outside, so you were not able to carry your baby.

Participant: Yes.

Interviewer: Yes.

Interviewer: Okay! Because you scared.

Participant: Yes.

Do you think you were allowed to pick up your baby?

Participant: Yes.

Interviewer: Were you allowed?

Interviewer: Did they say you can pick the baby?

Participant: Yes.

Interviewer: With the intestines outside?

Participant: The intestines, no it is not outside-

Interviewer: Before?

Participant: No.

Interviewer: When they were outside were you not able to pick up the baby?

Participant: No.

Interviewer: Did they say you can't?

Participant: Yes.

Interviewer: Did they tell you not to pick up the baby?

Participant: They were telling me-

Interviewer: That?

Participant: Yes.

Interviewer: What did they tell you?

Participant: To pick up my baby.

Interviewer: I mean when your baby's intestines were still outside, did they say you can pick up the baby?

Participant: Just for- (showing with hands)

Interviewer: Oh!

Participant: Ukuthi ngimyehlise embeteni, ngi hlale naye (Just to move her from the bed and sit with her)

Interviewer: Oh! So, you are able to pick up the baby just to sit with her?

Participant: No.

Interviewer: Standing?

Participant: Yes.

Interviewer: Okay. So, you wanted to pick up your baby to breastfeed and sit with her?

Is that what you wanted to do?

Participant: I started now.

Interviewer: You started now.

Participant: Yes.

Interviewer: But then, then you did not?

Participant: Mm.

Interviewer: Okay! Did the sister say you cannot do that?

Participant: For?

Interviewer: When your baby still had intestines outside, did the sisters and the nurses say No! mother you cannot pick up your baby?

Participant: No.

Interviewer: Then why did you not pick up the baby?

Participant: I was scared.

Interviewer: You were scared.

Participant: Yes.

Interviewer: Okay!

Interviewer: When I asked you about how the hospital stay and the medical condition has affected you as a mother and as a person, you said you are stressed. You are stressed because you want to see how your baby is doing-

Participant: Yes.

Interviewer: You want to see if your baby has eaten and that you want to know if your baby has slept well.

Participant: Yes.

Interviewer: Yes.

Interviewer: And I asked if you think it is important for you as a mother not to be separated from your baby. You said yes, it is important for you not to be separated and you wish that the hospital can transfer your baby to another hospital. When you say to another hospital, which hospital are you talking about?

Participant: Tembisa.

Interviewer: Tembisa because it is nearer to where you stay.

Participant: Yes.

Interviewer: Okay! When I asked you why it is difficult to care for your baby, you said because you see your baby after two weeks.

Participant: Yes.

Interviewer: And you only come Mondays and Fridays.

Participant: Yes.

Interviewer: You told me that the family is supporting you because they are giving you money to catch a taxi to come and see the baby.

Participant: Yes.

Interviewer: Okay! And when I asked you-

Participant: (Sniffles)

Interviewer: Again, what do you think the hospital can do for you to make it easier to care for your baby, you said if you can be able to stay here in the hospital-

Participant: Yes.

Interviewer: And not come to visit-

Participant: Yes.

Interviewer: You want to see your baby, you want to breastfeed, and you want to see how your baby is doing.

Interviewer: Yes. you also said what is helping you to care for your baby, the enablers are that the Doctors are helping your baby by giving your baby medication.

Participant: Yes.

Interviewer: Okay!

Interviewer: That is the end of our interview, do you have any questions?

Participant: No.

Interviewer: You can ask me anything.

Participant: I don’t have questions.

Interviewer: You don’t have questions.

Participant: Yes.

Interviewer: Okay. I have a question for you.

Participant: I see this has made you so emotional, you feel stressed, you wish that you can spend more time with your baby and not travel.

Participant: Yes.

Interviewer: Do you want me to refer you for psychological help, the hospital Psychologist?

Participant: Yes.

Interviewer: Do you think you need to be seen?

Participant: Yes.

Interviewer: Do you need counselling?

Participant: Yes.

Interviewer: You need counselling. Okay! I will talk to the sisters in the ward and then I will ask them what the procedure is, and we will take it from there.

Interviewer: Thank you very much for your time.

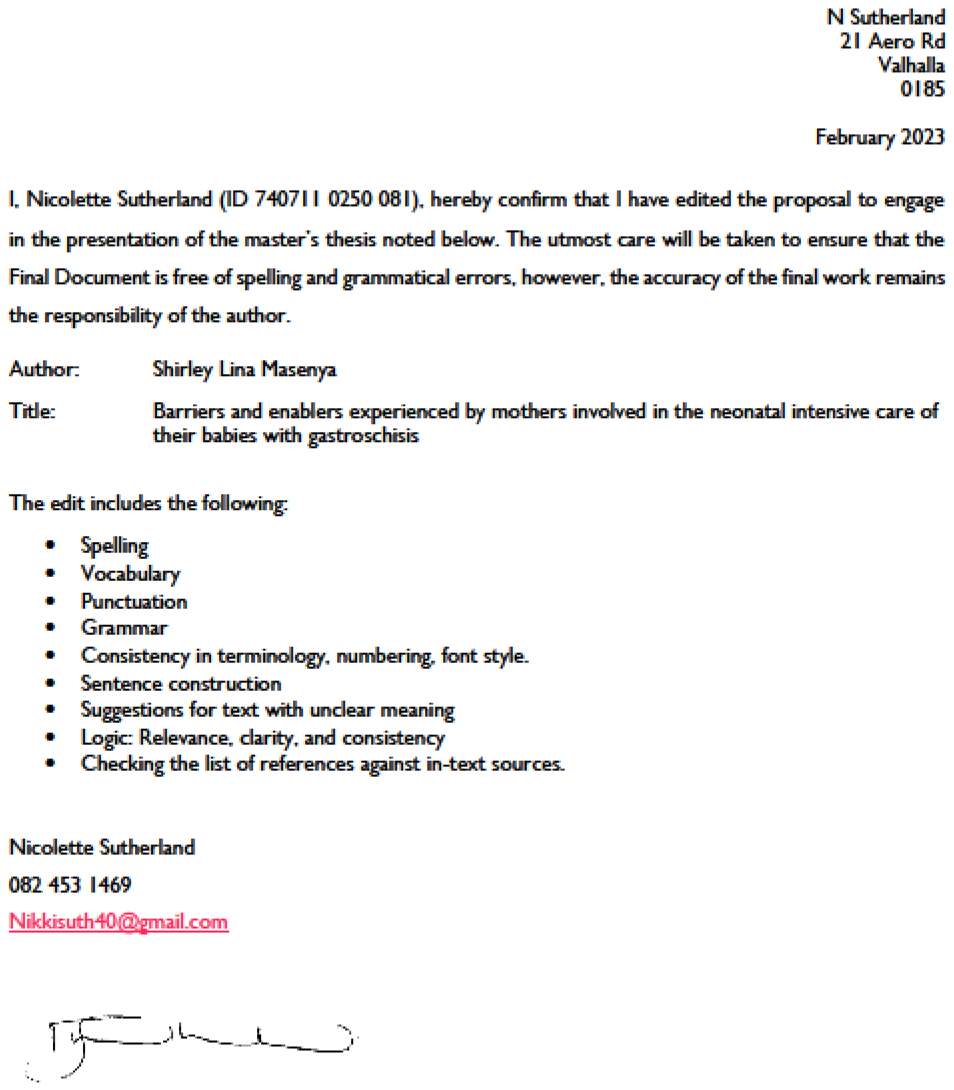
Participant: Yes.

Interviewer: Thank you very much for your time. Do you think this interview helped you in some way?

Participant: Yes.

-end-

ANNEXURE I – EDITOR'S LETTER



N Sutherland
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February 2023

I, Nicolette Sutherland (ID 740711 0250 081), hereby confirm that I have edited the proposal to engage in the presentation of the master's thesis noted below. The utmost care will be taken to ensure that the Final Document is free of spelling and grammatical errors, however, the accuracy of the final work remains the responsibility of the author.

Author: Shirley Lina Masenya

Title: Barriers and enablers experienced by mothers involved in the neonatal intensive care of their babies with gastroschisis

The edit includes the following:

- Spelling
- Vocabulary
- Punctuation
- Grammar
- Consistency in terminology, numbering, font style.
- Sentence construction
- Suggestions for text with unclear meaning
- Logic: Relevance, clarity, and consistency
- Checking the list of references against in-text sources.

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