

**THE POST-FACILITY DISCHARGE CHALLENGES ON THE PSYCHO-SOCIAL
WELL-BEING OF MOTHERS CARING FOR PRETERM BABIES IN JINJA
REGIONAL REFERRAL HOSPITAL**

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**A DISSERTATION SUBMITTED TO THE FACULTY OF PUBLIC HEALTH, NURSING AND
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Declaration

I hereby declare that to the best of my knowledge this research paper titled “**The Post-facility Discharge Challenges on the Psycho-Social Well-being of Mother Caring for Preterm Babies in Jinja Regional Referral Hospital**” is my original work and has never been submitted to any university or other institution in fulfilment of an academic award, publication or otherwise. I henceforth present it for the award of a Master’s degree in Public Health Leadership at Uganda Christian University of Mukono.

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Approval

This is to certify that this research report titled “**The Post –facility Discharge Challenges on the Psycho-Social Well-being of Mother Caring for Preterm Babies in Jinja Regional Referral Hospital**” has been submitted with my approval.

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Date: 20/04/2025

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Dedication

This work is dedicated to my sisters Doctor Namazzi Gertrude, and Prossy Kalema, my brother Kiwanuka Francis, Mulondo Joseph, and my mother Nansamba Stella plus my daughter Kiweewa Favour who tirelessly supported me in everything, and may the almighty God yield them ample rewards.

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Abbreviations

HF	Health Facility.
HWs	Health Workers
KMC	Kangaroo Mother Care
MoH	Ministry of Health
PFD	Post-Facility Discharge
UDHS	Uganda Demographic Health Survey.
WHO	World Health Organization
REC	Research Ethics Committee.
UCU	Uganda Christian University.
NICU	Neonatal Intensive Care Unit
JRRH	Jinja Regional Referral Hospital.

Definition of study concepts

1. **Preterm** is defined as a baby born alive before 37 weeks of pregnancy is completed. There are sub-categories of preterm birth, based on gestational age:
 - Extremely preterm (less than 28 weeks)
 - Very preterm (28 to less than 32 weeks)
 - Moderate to late preterm (32 to 37 weeks) (WHO,2018)
2. A caregiver refers to the individual who provides physical, emotional, and psychological support to preterm infants and their families after discharge (American Academy of Pediatrics, 2019).
3. **Post-facility discharge** refers to the period following a patient's release from a healthcare facility, such as a hospital. This period is very critical for a patient, particularly those with complex medical needs, as they transition from institutional care to self-care or community-based care. (Agency for Health Care and Quality).
4. **Psycho-social well-being** refers to an individual's overall mental, emotional, and social health. It encompasses various aspects, including:
 - Psychosocial well-being, for example, emotional stability and resilience.
 - Social well-being, for example, relationships and social support.
 - Cognitive well-being, for example, problem-solving and coping skills.

Abstract

Background: Prematurity is the leading cause of mortality among newborns and infants under 1 year. The World Health Organization estimates that 15 million babies are born before term every year. Several interventions have been put in place to save the lives of preterm babies at the health facility level and less at the community level, and for the caregivers of preterm babies during the post-facility discharge. The post-facility discharge death among the preterm ranges from 11% to 28%. This study explored the post-facility Discharge Challenges on the Psycho-Social Well-being of mothers caring for Preterm Babies in Jinja Regional Referral Hospital.

Methods: This study was conducted at Jinja Regional Referral Hospital in eastern Uganda. It employed a qualitative approach with two data collection phases. Phase 1 of data collection was in-depth interviews with mothers caring for preterm babies discharged from inpatient services but still attending premature clinic hours. Phase 2 is composed of Focus Group Discussions. We held 30 in-depth interviews and three FDGs 8 respondents each session, and a thematic approach to data analysis was used.

Results: There were increased psycho-social challenges among mothers caring for preterm babies at home because of psychological distress and sleep deprivation. mothers perceived their babies as medically vulnerable alongside other post-facility discharge challenges like feeding, which was universally shared among all mothers, keeping the baby warm, and also juggling routine household activities. Spouses, relatives, and friends were the sources of emotional support. Mothers suggested that developing a peer-to-peer intervention can mitigate post-facility discharge challenges and improve post-facility discharge outcomes.

Conclusion: The post-facility discharge challenges are attributed negatively to the psycho-social well-being of mothers. The majority of the mothers suffered psychological issues, including self-isolation and departing from social connections, sleep deprivation, and re-admission of the infants.

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

1.1.1 Historical Background.

Preterm birth is a significant public health concern affecting millions of families worldwide. The World Health Organization (WHO) estimates that 15 million babies are born preterm each year, resulting in a global preterm birth rate of approximately 11% (World Health Organization, 2021). This organization also reported that around 1 million children die due to complications from prematurity at birth and before the age of five. Preterm birth is the leading cause of death among children, accounting for 18% of all deaths among those under 5 years and as much as 35% of all deaths during the neonatal period. It is further noted that 1 in 10 live births occur before term (PMNCH, 2013). On average, 12 % of preterm babies are born in developing countries and 9% in developed countries (WHO, 2012).

A study conducted in Asia and sub-Saharan Africa (SSA), including countries like Pakistan, India, and Ghana, reported high preterm birth rates that contribute to 49% and 40% of all infant deaths in these regions, respectively. Additionally, the study found that preterm birth is on the rise among adolescent mothers (Global Health, 2022).

Preterm infants account for nearly 0.7% of all hospital admissions in Uganda. They are responsible for approximately 11.1% of mortality in children under five years, as well as 5% of deaths among children of all ages (Beck et al., 2010; Egesa et al., 2020; MoH, 2017). Furthermore, each year, there are over 226,000 preterm births in Uganda, with 12500 dying before their first birthday, and over 9,830 preterm babies under five years

old dying (UHNN & USAID, 2018). According to a survey conducted in Uganda between 2015 and 2019 using the district health management information system, the incidence of preterm birth admissions steadily increased in central and eastern Uganda (UNIPH, 2021). Moreover, the World Health Organization suggests that strengthening the community health worker system is the best tactic to diminish the post-facility discharge challenges using peer support intervention by linking mothers in the community to share knowledge on the appropriate care outside the health facility.

1.1.2 Conceptual Background.

The health workers regularly assess inpatients and coordinate hospital discharge plans when patients no longer require inpatient treatment. Information on post-facility discharge care is discussed with patients and their caregivers (Johns Hopkins, 2023). Patients are strictly required to follow the instructions given by health workers during the post-facility discharge to avoid readmission.

A post-facility discharge plan is like preparing a game, as each party involved must understand their role. However, the stress and difficulties faced by patients and caregivers during their stay at the health facility make it common for them to forget or misinterpret the instructions given by the health Workers at the point of discharge, resulting in post-facility discharge challenges (TriageLogic, 2023).

‘Post-facility discharge’(PFD) refers to a period when the inpatients are no longer required to receive treatment within the health facility and are sent home with an option to follow-up instructions from the health workers.

Post-facility discharge challenges are common, particularly among mothers of preterm babies, who often face significant challenges, including managing their baby's complex medical needs, navigating the healthcare system, and coping with the emotional and financial stress of caring for babies (Mugisha et al., 2022). These challenges affect the psycho-social well-being of caregivers and are prevalent in low- and middle-income states (Abayon et al., 2024; Phetsitong et al., 2022).

The caregivers of preterm babies experience PFD difficulties, which are health-related, individual, and those that arise from culture and household. The post-facility discharge plan may include taking medicines at the right time and in the right quantity, changing and caring for bandages, and tasks (Johns Hopkins, 2023). Additionally, the PFD care for preterm babies may include ensuring knowledge of who to contact in case of questions or problems, complying with follow-up appointments, breastfeeding, maintaining skin-to-skin or kangaroo mother care (KMC), limiting outdoor visits, and living in a good hygienic environment with infection control (Apollo Cradle, 2023).

Studies have shown that during the PFD, mothers are often unable to provide adequate care to their babies, as they did earlier while in the hospital, and the cause of this decline is not clear (Kwesiga et al., 2022). The psychosocial well-being of mothers caring for preterm babies can be stressful and emotionally challenging (Lefkowitz et al., 2020). Studies have also shown that caregivers of preterm babies are at increased risk of anxiety, depression, and post-traumatic stress disorder (Vigod et al., 2018).

1.1.3 Contextual Background

Jinja Regional Referral Hospital is a government-owned referral hospital that was established in the 1930s as a health unit for World War II combatants and prisoners of war from Kimaka. Later on, it was upgraded to a district hospital, and in 1995 it became the regional referral hospital for the eastern region.

The hospital is located in the southeastern part of Uganda practically in the Busoga region, it is located on two sites and offers a whole range of services except the super-specialized, the second site is the Children's Hospital locally known as Nalufenya Hospital.

The hospital serves approximately a population of 4.5 million in a catchment area comprising 1 city and 11 districts (Jinja City, Jinja, Iganga, Kamuli, Mayuge, Namutumba, Bugweri, Buyende, Luuka, Kaliro, Namayingo, Bugiri). The hospital also serves the neighbouring districts of Mukono, Buikwe, Kayunga, Buvuma, Busia, and Tororo among others. It also serves as a referral for 6 general hospitals both Private not for profit (PNFP) and some private for-profit (PFP) within the region (Kakira, Kamuli Mission Hospital, Nyenga, Buluuba, Kamuli district hospital, Kawolo, Iganga, Kagoma, and Bugiri general hospitals).

In addition, the hospital serves 22 health centre IVs namely: Budondo, Bugembe, Bugono, Bumanya, Kaliro, Buwenge, Busesa, Buyinja, Kidera, Mayuge, Kigandalo, Kityerera, Kiyunga, Malongo, Nakasongola, Mpumudde, Namwendwa, Nankandulo, Nankoma, Ngando, Nsinze and Walukuba.

Furthermore, the hospital has a functional neonatal intensive care unit (NICU) that handles special cases of newborns with complications from within and referrals. The cases managed include prematurity, low birth weight (LBW), birth asphyxia, respiratory distress syndrome, hypothermia, neonatal sepsis, and birth defects among others.

Premature babies are discharged from the NICU when they are stabilized and also following the estimated date of delivery. Before and at discharge mothers or caregivers are trained and equipped with knowledge to handle preterm while at-home caregivers are expected to honor the appointment of the review dates of clinic day hours which are usually done on Fridays until the preterm is six months.

According to Kwesiga et al., 2022 reported that Mothers are facing challenges during the post-facility discharge that caused a decline in good practices toward the care of preterm babies, a knowledge gap in regulating feeding intervals, and the number of times to do KMC and when to terminate. The focus is on the positive outcome of the preterm baby and the caregivers are currently ignored especially on their status of psycho-social well-being. The psycho-social well-being of mothers caring for preterm babies remains concerning in Jinja and Uganda and the reason is caring for vulnerable infants without active peer-to-peer links in the community and no visit from public health nursing to the caregivers after discharge.

1.2 Problem Statement

Approximately 15 million babies are born preterm globally every year, resulting in one million child deaths due to prematurity complications (World Health Organization, 2021). Uganda has a high preterm birth rate of 14 per 1000 live births (UNIPH, 2021). Jinja Regional Referral Hospital reports an average of 556 deliveries per month, with approximately 60 preterm births, accounting for 10.8% of total deliveries (Babirye, Z et al,2022). Despite advances in neonatal care, mothers of preterm babies often face significant challenges after discharge from the hospital, impacting their psychosocial well-being (Lefkowitz et al, 2018). However, these challenges are not well understood.

To address this, the MoH and partners such as Preterm Birth Initiative East Africa (PTBi-EA) have implemented effective interventions including Kangaroo Mother Care (KMC), breastfeeding practices, umbilical cord care, and infection control (Mukunya et al., 2021). Preterm babies are followed up through clinic hours/days until they are 18 months old, enabling them to thrive at home (World Health Organization, 2021).

Despite the efforts to improve care quality, mothers of preterm babies often experience heightened anxiety and depression (Mugisha et al., 2022). The transition from hospital care to home care can be overwhelming, with mothers shouldering numerous responsibilities for caring for delicate infants. However, the focus has been on preterm baby care, with no attention to caregivers' psycho-social well-being. Research on the post-facility discharge challenge faced by mothers and their perceived influence on psycho-social well-being is limited. This study aims to explore these PFD challenges and their perceived influence on psycho-social well-being, to make recommendations that inform the development of interventions and support services.

1.3 Research Questions.

- What are the post-facility discharge challenges encountered by mothers caring for preterm babies less than a year old?
- How do the post-facility discharge challenges affect the psychosocial well-being of mothers caring for preterm babies?
- What support do mothers caring for preterm babies receive to cope with the post-facility challenges?

1. 4 Study of Objectives

1.4.1 General Objective

To explore post-facility discharge challenges on the psychosocial well-being of mothers caring for preterm babies in Jinja Regional Referral Hospital.

1.4.2 Specific Objectives

- To explore the challenges mothers encountered while caring for preterm babies during post-facility discharge in the Jinja Regional Referral Hospital.
- To understand the perceived influence of post-facility discharge challenges on the psychosocial well-being of mothers with preterm babies in Jinja Regional Referral Hospital.
- To understand the support received by mothers to cope with the post-facility discharge challenges in Jinja Regional Referral Hospital.

1.5 Theoretical Framework

1.5.1 The Social Ecological Theory of Health

The social-ecological model of health states that an individual is embedded within a large social system, conceptualized broadly, and focuses on multiple factors that might affect health (Centers for Disease Control and Prevention, CDC,2007). According to Israel and colleagues, the social-ecological model narrates that health is affected by individuals, groups/communities, and social, physical, and political environments (Israel et al,2003). In addition, this model articulates key concepts and the meaning of health concerning the advanced definition of health by the World Health Organization, which noted that health is not merely the absence of disease but includes physical, mental, and social well-being (CDC, 2007). A four-level model of the factors affecting health is grounded in social ecological theory.

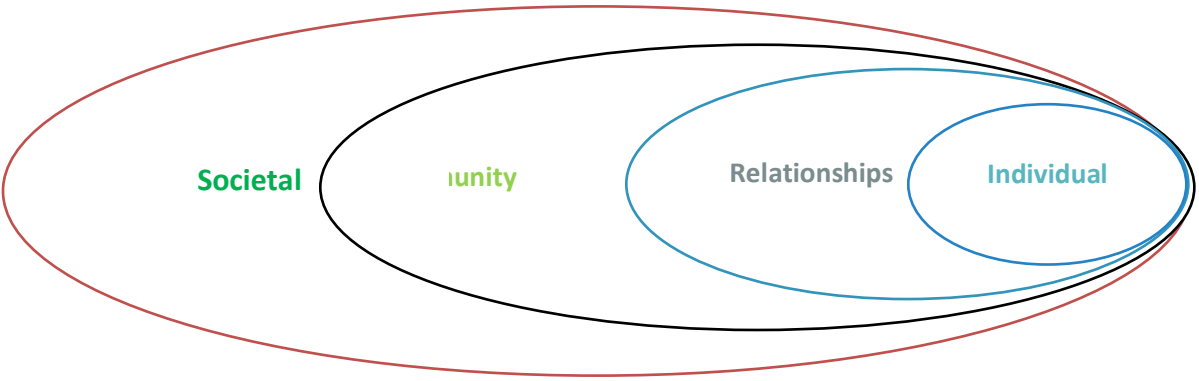


Figure showing the social ecological theory of health

Source: Centers for Disease Control and Prevention (CDC), 2007

1.5.1.1 Individual level

This is the First level where the Individual/mother characteristics influence behaviours, such as knowledge, attitudes, beliefs, and personality traits, and other personal characteristics, such as age, education, income, and health history (CDC, 2007; U.S National Institutes of Health, 2005). During the post-facility discharge period mothers' knowledge of caring for preterm, influences the health outcome of the baby, and in circumstances where mothers caring for preterm have gaps in some area of care, they are likely to face a lot of adversity. This study used this model to guide the process while exploring the individual-related challenge as far as caring for preterm babies during post-facility discharge is concerned.

1.5.1.2 Interpersonal relationships

Relationships include Interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support, and role definition, all of whom influence a person's behaviour and contribute to his or her experiences (Krug et al, 2002). This study used this model to identify actual relationships mothers caring for preterm babies have and how they contribute to their psycho-social well-being both positively and negatively.

1.5.1.3 Community level

Community explores the settings in which people have, social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations such as schools, health facilities, and neighbourhoods, and seeks to identify the characteristics of these settings that affect health (U.S National Institutes

of Health, 2005). This study shall explore the gap in community structures and partnerships that have not been geared toward increasing health services and empowering mothers caring for preterm babies.

1.5.1.4 Societal level

The fourth level focuses on the broad societal factors that favour or impair health, such as cultural and social norms, the health, economic, educational, and local, state, and social policies that regulate or support healthy actions and practices for disease prevention, early detection, control, and management. (CDC, 2007; Krug et al, 2002; U.S National Institutes of Health, 2005). The emphasis of this study was to look at the policies and information gaps that pose adversity to mothers who are caring for preterm babies in the study.

1.6 Significance

This study is considered beneficial to caregivers of preterm babies because it created awareness of the PFD challenges and the best ways the mothers could be supported to mitigate the avoidable post-facility discharge challenges.

Many researchers have explored the challenges faced by mothers caring for preterm babies, their experiences, and knowledge of providing care during the PFD. So, something that has not been tackled is the psycho-social well-being of the caregiver during the post-health care discharge. The study results generated new knowledge in this area that will fill the literature gaps.

In addition, the findings of the study are to assist stakeholders in policy-making to design new interventions and also review the care guidelines concerning managing

preterm babies during the PFD, which shall help create change and benefit the stakeholders as well as the community.

1.7 Scope of the study

1.7.1 Content scope

This study explored the post-facility discharge challenges encountered by mothers who are caring for preterm babies and how these challenges affected their psycho-social well-being. The study also explored the institutional challenge faced by mothers caring for preterm babies and discovered the strategies mothers employed at home to cope with post-facility discharge challenges.

1.7.2 Geographical scope.

The study was conducted in Jinja Regional Referral Hospital in Jinja city, which is located in the Busoga sub-region, in the eastern region of Uganda. It is approximately 81 kilometers, by road, east of Kampala, the capital city (Uganda Radio Network, 2019). It sits along the northern shores of Lake Victoria, near the source of the River Nile.

1.7.3 Time scope.

The Study took a period of seven months, from December 2023 to June 2024

CHAPTER TWO

LITERATURE REVIEW

2.1 The hardship of preterm birth

Globally, the World Health Organization estimates that 15 million babies are born before 37 weeks of pregnancy are completed every year, and the number of preterm babies is increasing (WHO & UNICEF, 2019). This interprets prematurity complications being the second cause of perinatal mortality after birth asphyxia in Uganda. However, prematurity complications are the leading cause of neonatal death worldwide. Similarly, of the 15 million preterm births that occur, over 84% happen between 32 to 36 weeks of gestational age (Walani, 2020). Prematurity is a great hardship to the caregivers because their babies are at risk of different abnormalities, such as visual and neurodevelopmental delay, compared to children born at term (Leung et al., 2018). Mothers or caregivers of preterm babies face many challenges during the post-facility discharge, which affects their psychosocial well-being. Preterm babies need around-the-clock or frequent care, like a minimum of 8 hours per day of kangaroo mother care to keep the baby warm occupies the mothers close to a full-time job.

2.2 Individual (mothers) challenges encountered caring for preterm infants during post-discharge.

Feeding problem, according to (Premji et al., 2017a), mothers with preterm babies experience challenges when it comes to feeding during the post-facility discharge. Despite using different methods, such as exclusive breastfeeding or bottle feeding, caring for preterm babies remains a challenge, including determining whether the baby is satisfied or not. Additionally, mothers caring for preterm babies face adversity in

feeding, in the way that they cannot rely solely on exclusive breastfeeding, like mothers with term babies. Preterm babies cannot suckle enough to satisfy them, and mothers must go the extra mile to carry out an expression of breast milk to supplement, and this challenge continues beyond three months post-delivery. According to a cohort study on the lactation status and breastfeeding challenges among mothers of preterm babies, it was revealed that 70% of enrolled infants were not able to feed exclusively at three months (Dong et al., 2022). However, the researchers feel there is a need to conduct another study to establish the attributes of PFD challenges on psycho-social well-being, which the previous research has not mentioned.

Inadequate knowledge of care, most infant mortalities that occur within the community are due to poor cord care practices, which attract infections, according to the study conducted by (Ndikom Chizoma & Oluwastosin, 2020). The study discovered that mothers' knowledge of umbilical cord care was low since mothers, before discharge from the health facilities, learn by observing others, and when they return home, the care deteriorates. Another study noted that two groups of mothers used breast milk for umbilical cord care and crude alcohol, respectively (Faheim et al., 2019). These studies were conducted in West Africa, and the researcher feels there was a gap to fill if another study is conducted in a different geographical location.

Attitude towards transition. Mothers caring for preterm babies struggle to make the transition from the health facility to establishing complete care at home (Boykova, 2016). Most have fear and are worried about making mistakes, especially first-time mothers.

2.3 Community, household-related challenges being faced by mothers caring for preterm babies during post-facility discharge?

No male involvement. Literature shows that mothers caring for preterm infants are new to the role and need support from their spouses. However, preterm infant mothers feel it's stressful to juggle many tasks to meet the infant's proper care. Caring for the preterm means a lot, including washing and cleaning the baby and its surroundings, keeping the baby warm, and feeding. When asked to provide a hand of support, spouses may view it as inconvenient (Garti et al., 2021).

Gender roles and societal expectations for women, both productive and reproductive roles. In African traditional society, women perform most of the domestic work, such as gardening, laundry, preparing meals, fetching water, and other household chores (Musoke, D., 2014). These roles haven't changed, and women still perform most household activities, occupying most of their time and dedicating less care to their babies. It's not only the baby that is affected but also the mothers, who get less time to rest, making caring for the baby stressful and affecting their psycho-social well-being.

Cultural norms. When the baby is born, there are rituals performed on the baby in African traditional society, which is believed to raise the children, and this is done by grandparents and the traditional rituals are done using the umbilical cord (Buys & Gerber, 2021a). However, due to the long stay of preterm in the hospital neonatal units, the cord drops off, and the health workers dispose of them as medical waste. This becomes a challenge for mothers when they return, as acceptance of the child by the family

becomes a serious matter. They presume the infant will cause problems for the entire clan because their umbilical cord wasn't dedicated to the ancestors.

Dependence on spouses and relatives regarding the provision, especially the financial provision. Women in a household cannot make sole decisions when a need to seek healthcare services arises. Most rural women request financial provisions from their spouses or elders. This becomes a challenge for the mothers when the spouses or relatives delay providing transport costs and other expenses incurred while seeking healthcare services for preterm babies. Similarly, UDHS reports that most women in Uganda do not make decisions on important matters of the household, including healthcare. Furthermore, among the currently married women aged 15-40, 40.3% don't participate in making specific household decisions either alone or jointly with their husbands (UDHS, 2022).

2.4 Institutional-related challenges faced by mothers with preterm babies during post-discharge.

Two-hour care. The quality of care for preterm babies reduces significantly during the post-facility discharge when the mother remains the primary caregiver at home, unlike during the neonatal unit stay in the hospital where the nurses and doctors provide close monitoring (Garti et al., 2021). The researcher feels there was a need to conduct another study because, since the Ministry of Health has been implementing the national male participation strategy, the two-hour care should not be a challenge in households with two partners.

Long distance to the health facilities. This is an obstacle to mothers caring for preterm babies. The World Health Organization recommends that infants who are born before term or with any birth complication should be monitored and reviewed by health workers until the baby reaches 18 months (WHO,2005). However, in Uganda, there is decentralization of health services; at the parish HCII, sub-county HCIII, county (constituency) HCIV, and at the district level general hospital. Furthermore, paediatricians are based at HC IVs and higher health facilities.

Poor quality of services coupled with chronic shortages of adequate staff and drugs in the health facilities. According to (World Health Organization, 2021) there should be adequate supplies and sufficiently trained and competent staff on site, with clear descriptions of their responsibilities. However, the researcher feels there was a gap to bridge because during the post-facility discharge, the mothers are on their own with no community-based intervention that reviews the baby, and the caregivers are responsible for meeting all the costs of drugs, such as multivitamins.

Lack of post-facility community follow-ups. Mothers caring for preterm babies revealed that, once they leave the health facility, they are on their own, with no follow-up while in the community, not even a phone call from health workers for guidance on how to improve the care toward the preterm infants (Kwesiga et al., 2022; Lyne et al., 2022). Mothers believe their babies are medically vulnerable, and it's difficult to provide care in all areas, such as cleaning and administering medicines, and they need guidance from the health workers to achieve medical stability while at home (Buys & Gerber, 2021a).

Inadequate health education, particularly on Kangaroo Mother Care, is a very important factor for the growth of low birth-weight and preterm infants (Olawuyi et al., 2021). Mothers are enthusiastic about doing KMC during admission, but when they leave the hospital, they reduce the recommended number of times the baby should receive KMC per day (Lyne et al., 2022). There was a need to conduct a study to establish the deterioration and its influence on the psycho-social well-being of the caregiver. The focus has been on educating mothers to provide the best care for their babies, but not on how to deal with the situation concerning their psycho-social well-being.

Unprepared discharge due to high admissions and limited space in the health facilities, and because of the principle of the expected discharge date (EDD) it means that mothers with preterm infants must stay in neonatal care units until the period the baby is supposed to stay is covered, and the process of preparing mothers of preterm infants to take care their babies while at home is often left until shortly before the baby is to be discharged, commonly leaving mothers unprepared and lacking in knowledge to care for the preterm babies (Ingram et al., 2016).

Conduct and attitude of health workers. Literature shows that some mothers have a negative attitude toward health workers, which hinders them from seeking care for their infants after facility discharge, based on previous visit experiences (Sialubanje et al,2015). Additionally, it was revealed that 80% of mothers reported that health workers were harsh, abusive, arrogant, and rude towards them (F. Nyakaisiki,2012; Wilunda 2014). The researcher feels there is a gap to bridge in this literature because the authors did not consider the workload of the health workers and their ratios, as an

overwhelmed health worker may be stressed by their workload and may communicate in a tone that could be interpreted as a bad attitude or arrogance.

2.5 Attributes of the post-facility discharge challenges on the psycho-social well-being of mothers.

Stigma. The community and families do not always embrace preterm infants, and some individuals do not like them as much as those born at term. Mothers of preterm infants feel affected by this kind of experience from the community, which makes them uncomfortable while parenting and caring for their preterm babies (Lesley S. Taylor, 2016). Another study noted that mothers caring for small babies experience negative treatment from individuals within their family and social circle (Sakyi KS Owusu PG et al., 2020). Due to the nature of the baby, some individuals are unfamiliar with preterm babies before, so the appearance of the baby is judged, inflicting stigma on the mothers and infants.

Emotional disturbance. According to a study conducted in Ghana, mothers who are caring for premature babies are subjected to feelings of emotional disturbance (cognitive), which gradually result in depression (Lesley S. Taylor, 2016). Another study suggested that mothers caring for premature infants have negative emotional experiences developing from a sense of feeling of guilt and responsibility for the baby being born before the completed gestational age (Lomotey et al., 2019). Similar findings have presented that the mothers of preterm infants have a higher level of depressive symptoms that extend beyond the postpartum period, with very limited reduction in symptoms (Leahy-Warren et al., 2020).

Postpartum depression. Literature shows that mothers caring for preterm infants experience depression extending beyond the sixth week after birth due to overwhelming needs and care for premature babies. It was also revealed that mothers with depression symptoms and depressed mothers demonstrated less confidence in their caretaking role (Premji et al., 2017a). The same source portrayed that 38% of mothers with preterm infants were at increased risk of depression within their first year of post-facility discharge. It was also revealed that 7% of Ugandan women aged 15-49 attending Postnatal care were diagnosed with depression and anxiety, and 20% of the diagnosed women received treatment for depression and anxiety (UDHS, 2022).

Readmission. Due to poor care practices, resulting in inadequate knowledge among preterm infant caregivers. Preterm infants are at greater risk of readmission into the health facility within 30 days after initial discharge. The results of the retrospective cohort study argued that hospital readmission is high among preterm infants compared to term infants, with a readmission odds ratio of 2.34, meaning the odds were associated with readmission among preterm infants (Amsalu et al., 2022). It was also noted that infections, sepsis, hypothermia, and jaundice were highly linked to readmission.

2.6 The support to the mothers of preterm babies during the post-facility discharge.

Mothers-to-mother support. This is when the mothers reach out to others who are caring for the preterm babies and share experiences. It's more about learning from each other to provide the best care for their children. "Parents also felt supported through

organized support groups and through the provision of an environment where parents can meet and support each other” (Brett et al., 2011; Lindberg et al., 2009; Lyne et al., 2022). However, this type of support in Uganda is not organized, as there is no clear source of peer-to-peer intervention or training for peer mothers to reach out to other mothers who face challenges while caring for their preterm babies during the post-facility discharge.

Support from experts. Health workers are trusted by mothers, and any kind of guidance offered by Health Workers to mothers is very crucial to promoting their psycho-social wellbeing (Lyne et al., 2022). Experts provide support to mothers caring for premature babies through behavioural care talks, which support them in acquiring knowledge in essential care areas such as breastfeeding, kangaroo mother care, and baby massage, among others (Koppel et al., 2022). However, this kind of support is institutional-based, and this study found out how the facility-based program can support while at home. Furthermore, these studies were conducted in developed countries, and this kind of support is provided through video conferencing; in Uganda, some people do not own devices that support these programs.

Relatives’ support. Most families in Africa are extended; when a mother returns home from the hospital neonatal unit, they receive warm support from the extended family members, such as grandparents, in-laws, and siblings (Craig et al., 2015). Relatives support mothers with premature babies through childcare and other household activities while mothers are concentrating on their preterm infants.

Spouse support. Fathers are the primary caregivers in the household, and studies showed that most of the mothers with preterm babies revealed that their spouses were supporting and understood the conditions and nature of the baby they had (Premji et al., 2017). Additionally, mothers revealed that their spouses provided important social support when they felt isolated after facility discharge. However, the researcher feels that this spouse support only reached those in marriage unions, while single mothers and abandoned mothers perhaps suffered a lot, and this study sought to hear from both sides and what kind of support they received.

2.7 Literature review summary and gap

The literature review aimed at identifying various post-facility discharge challenges and the perceived influence of such challenges on the psycho-social well-being of mothers caring for preterm babies below one year. The studies reviewed were conducted in Uganda, Kenya, Tanzania, Ghana, Nigeria, Ethiopia, Pakistan, and India among others. Studies showed that PFD challenges such as feeding, and performing kangaroo mother care while juggling household chores, attributed negatively to the psychosocial well-being of mothers caring for preterm babies. On the other hand, with the availability of supportive healthcare providers and peers, mothers were able to cope with PFD challenges.

Overall, the literature highlights the growing body of research on the experiences of mothers caring for preterm babies, there is a significant knowledge gap in understanding the post-facility challenges faced by these mothers and their impact on psycho-social well-being.

The specific gaps in the literature, there is a growing body of research on the experiences of mothers caring for preterm babies during the health facility stay, but there is limited focus on the post-facility challenges. Additionally, insufficient attention to psycho-social well-being. There is a need for more studies to explore the perceived influence of PFD challenges on the psycho-social well-being of caregivers of preterm babies. Furthermore, there is a need for studies to explore the PFD interventions aimed at improving the psychosocial well-being of caregivers of preterm babies and to balance the equation because more efforts, interventions, and focus have been given to the outcome of the babies. Furthermore, there is a need for exploratory research to have a deeper understanding of the PFD challenge on the psychosocial well-being of caregivers of preterm babies.

CHAPTER THREE

RESEARCH METHODS

3.1 Research Design

This study employed a phenomenological design. The rationale for this design was to facilitate the collection of data from several individuals. It also guided the researcher in obtaining detailed information concerning common post-facility discharge challenges experienced by mothers of preterm babies and their perceived influence on psychosocial well-being. Furthermore, it provided a combination of textual and structural descriptions of what and how caregivers experienced the situation while giving care to the infants (Creswell, W, 2007). The data collection tools and consent forms were translated into the local language (Lusoga).

3.2 Study Population/ Participant

The study population consisted of mothers with preterm babies under one year at the time of recruitment for data collection. These babies were still receiving outpatient care at Jinja Regional Referral Hospital's neonatal follow-up clinic and had been discharged from the health facility at least four weeks before the study's recruitment. According to the Uganda National Institute of Public Health, the national-level preterm birth admissions distribution indicated a steady increase in central and eastern Uganda between 2015 and 2019. Jinja Regional Referral Hospital was chosen because it serves patients from various regions and lower health facilities, which enabled the researcher to obtain the necessary sample size of participants during the study period.

3.3 Selection Criteria

Inclusion criteria: Study participants were mothers who delivered a “preterm baby” (baby born at less than 37 weeks of pregnancy) and whose babies were discharged alive from JRRH NICU but were less than one year old at the time of data collection.

Exclusion criteria: Mothers whose preterm babies were still admitted to the NICU or inpatient care.

3.4 Study Site Map

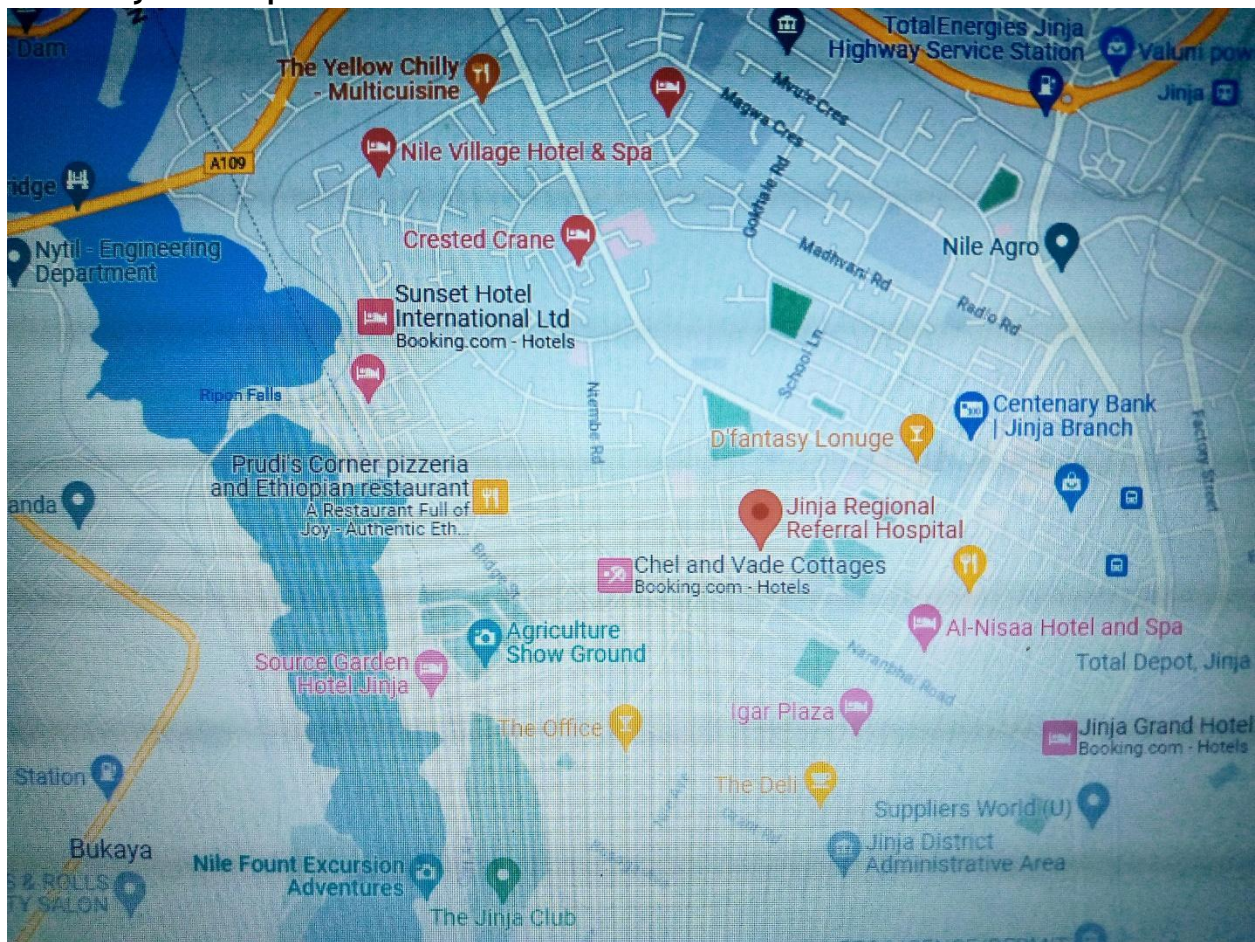


Figure 2: Study site map

Source: Google Maps

3.5 Sampling Procedure

The study utilised non-probability sampling; this method was chosen because its primary goal was to generate rich information that could only be obtained from a specific group of people (Acharya et al., 2013; Nayeem Showkat & Huma Parveen, 2017). A purposive sampling strategy was employed to select mothers with preterm babies who had been discharged from the hospital at least 4 weeks before recruitment. This study recruited mothers from preterm follow-up clinics.

The first participant was identified through a referral from the paediatrician nurse on duty at the clinic day. Subsequent participants were identified through referrals to pediatric nurses who had been involved in the care of preterm babies. These healthcare providers were aware of mothers' experiences and challenges during the PFD. The researcher approached the referred mothers, explained the study purpose and procedures, and obtained their informed consent before beginning the in-depth interview.

3.5.1 Sample Size

S/N	Category	No of participants
1	In-depth Interviews (IDI)	30
2	Focus Group Discussion	3 Sessions of 6-8 participants

Table 1 shows the sample size distribution

3.6 Data collection instruments

The data was collected using the in-depth interview guide, it was chosen because of its unique advantages in collecting qualitative data in a way that the researcher could

tailor the questions to ask the participants to get rich stories and the full information he/she needed, it also helped to understand the process of events, what and how they experienced PFD (Etikan Ilker, 2017). Additional data was gathered using the Focus Group Discussion (FGD), a field method that brought together small homogeneous groups composed of participants to discuss PFD challenges, and the data was collected using an open-ended guide. It was chosen because it doesn't require the participants to be literate to participate in the study, but it was also useful in capturing health beliefs and exploring complex issues.

3.6.1 Data Collection Procedure

Mothers were contacted at the NICU follow-up clinic during post-facility discharge visits. The mothers were introduced to the study, and those who showed interest were taken through the information sheet, which was translated into Lusoga, and after agreeing to participate verbally then they signed the informed consent form. The interviews were conducted within the hospital premises under trees and tents where the participants were comfortable sharing. The interviews were face-to-face with the mothers and were tape-recorded. The interviews lasted between 45-60 minutes. The FGDs recruited 6-8 participants per session. 3 sessions were conducted, and each session lasted for one and a half hours. The interviews were conducted by the principal investigator and one trained, experienced research assistant in qualitative research.

2.6.2 Data Quality /Error Control

The interview guide was pretested and refined as needed. The interviews were conducted by trained, experienced researchers in qualitative data collection. Data was recorded both on paper and audio recorders, and the researcher ensured that all the

questions on the interview guide had a response to ensure completeness. During the interview, the researcher was objective but not subjective to all responses to avoid bias, and the Lusoga audio recordings were transcribed verbatim, and the transcripts were checked for accuracy. Data saturation was achieved after conducting 30 in-depth interviews with caregivers for preterm babies. Saturation was determined through regular data analysis and coding, which revealed that no new themes or codes emerged after the 25th interview. The research team held debriefing sessions to discuss emerging themes, and a data table was used to track the emergence of themes. The final five interviews served to confirm the existing themes and provide further in-depth analysis.

2.6.3 Data Analysis and Management

The thematic analysis was used to analyze data, following a phenomenological approach. It was chosen because it helped in identifying and interpreting the main themes. The data analysis took all six steps of thematic analysis, that is, familiarization with data and transcription, coding, generating initial themes, reviewing themes, defining and naming themes, and generating reports (Creswell, W, 2007). Additionally, data was transcribed using Express Scribe transcription software and then imported into Microsoft Word. Furthermore, the final analysis was conducted using NVivo Pro 14v software, which summarized and categorised themes. Two data analysts, one with a Master of Health Services Research and another with a Bachelor of Social Work and Social Administration, worked independently and held several meetings to discuss the identified themes.

3.7 Ethical Consideration

This study was conducted following the principles of working with human subjects. The researcher also obtained approval from the Research Ethics Committee of Uganda Christian University and the research committee of Jinja Regional Referral Hospital, where the data was collected. The study participants were asked for voluntary participation, and informed consent was sought before their involvement. Privacy and confidentiality were safeguarded throughout the entire study process, and no personal identifiers of the participants were captured. Both the researcher and the research assistant acquired a certificate in good clinical practice.

3.7.1 Confidentiality

The sensitive personal identifiers of the participants were not captured. All information collected was kept by the researcher on password-protected devices. However, the local research ethics committee may have had access.

3.7.2 Privacy

The interviews took place in a private location within the health facility, in unoccupied spaces that were chosen by the participant; no participant was interviewed in a place where they felt uncomfortable.

3.8 Limitations of the Study

This study had some limitations. The study was conducted in one hospital, which may not be representative of all mothers with preterm babies in Uganda. The study used a non-probability sampling method, which may not have allowed for the generalizability of the findings. The study was not able to establish the causality between the post-facility discharge challenges and the psycho-social well-being of mothers caring for

preterm babies. Additionally, the study relied on self-reported data, which may be subject to bias.

CHAPTER FOUR

RESULTS

The results presented are from 30 mothers /respondents and 3 sessions of focus group discussions, whose particulars are shown in Table 1 below.

Mother's code	1. Age of mother at birth.	2. Marital status?	3. Parity.	4. Mode of delivery .	5. Gestational age?	5a. Defined preterm.	6. Number of babies delivered .	7. Enter Birth weight (grams)	7 a Birth weight second baby.	8. Lengthy stay at the health facility (days)	Place of birth .
PFD/PREM1	23	Married	2	C-section	29	Very preterm	Twins	1800	1900	14	HF
PFD/PREM2	31	Married	5	SVD	30	Very preterm	Single	1500		14	HF
PFD/PREM3	29	Married	3	SVD	34	late preterm	Twins	1980	1970	21	HF
PFD/PREM4	27	Married	3	SVD	36	late preterm	Single	2100		7	HF
PFD/PREM5	33	Separated	5	C-section	30	Very preterm	Twins	1100	1200	9	HF
PFD/PREM6	20	Single	1	SVD	32	Very preterm	Single	1800		9	HF
PFD/PREM7	29	Married	4	SVD	30	Very preterm	Single	1600		7	HF
PFD/PREM8	22	Single	2	C-section	29	Very preterm	Single	1450		20	HF
PFD/PREM9	24	Single	1	SVD	36	late preterm	Single	2200		10	HF
PFD/PREM10	21	Single	1	SVD	29	Very preterm	Single	1400		17	HF
PFD/PREM11	27	Married	3	SVD	34	late preterm	Single	2100		7	HF
PFD/PREM12	40	Married	3	SVD	27	Extremely preterm	Single	1200		28	HF
PFD/PREM13	29	Married	2	C-section	29	Very preterm	Single	1800		21	HF
PFD/PREM14	33	Married	5	SVD	30	Very preterm	Single	1500		14	HF
PFD/PREM15	23	Married	3	SVD	35	late preterm)	Twins	1980	1970	7	HF
PFD/PREM16	27	Married	3	SVD	36	late preterm	Single	2100		7	HF
PFD/PREM17	33	Married	5	SVD	30	Very preterm	Single	1900		7	HF
PFD/PREM18	20	Single	1	SVD	32	Very preterm	Single	1800		21	HF
PFD/PREM19	29	Married	3	SVD	28	Extremely preterm	Single	1600		30	HF
PFD/PREM20	23	Married	2	C-section	30	Very preterm	Single	1430		13	HF
PFD/PREM21	24	Single	1	SVD	37	late preterm	Single	2200		8	HF
PFD/PREM22	19	Single	1	SVD	29	Very preterm	Single	1400		23	HF
PFD/PREM23	27	Married	3	SVD	34	late preterm	Single	2100		9	HF
PFD/PREM24	30	Married	4	SVD	28	Extremely preterm	Single	1100		14	HF
PFD/PREM25	23	Single	2	C-section	29	Very preterm	Single	1450		7	HF
PFD/PREM26	24	Single	1	SVD	36	late preterm	Single	2000		7	HF

PFD/PREM2 7	21	Single	1	SVD	29	Very preterm	Single	1400		21	HF
PFD/PREM2 8	27	Married	3	SVD	34	late preterm	Single	1900		7	HF
PFD/PREM2 9	40	Married	6	SVD	28	Extremely preterm	Single	1200		28	HF
PFD/PREM3 0	26	Married	2	SVD	29	Very preterm	Single	1450		14	HF

Table 2 shows the participants' particulars

4.1 Major Themes and their corresponding

Five themes were identified to describe the post-facility discharge challenges on the psycho-social well-being of mothers caring for preterm babies. The results are presented in the form of themes and their corresponding subthemes.

No

No	Major Themes	Sub-themes
1	Full-time care to meet the special needs of preterm.	<ul style="list-style-type: none"> a) Feeding preterm. b) Keeping the baby warm/thermal control. c) Hygiene and infection prevention.
2	Mothers perceived their babies as medically vulnerable.	<ul style="list-style-type: none"> a) Medically ill baby. b) Low growth.
3	Financial constraints.	<ul style="list-style-type: none"> a) The cost of medicines and formula. b) Transport cost.
4	Mothers' health and psycho-social wellbeing.	<ul style="list-style-type: none"> a) Psychological distress. b) Sleeping deprivation. c) Social Relationships with others.
5	Social support.	<ul style="list-style-type: none"> a) Emotional support. b) Instrumental support. c) Informational support.

Table 3 shows major themes and their sub-theme.

4.2 The post-facility discharge challenges encountered by mothers caring for preterm babies.

4.2.1 Theme 1: Full-time care to meet the special needs of preterm.

This theme highlights the amount of time that mothers give over to care for their preterm babies during the post-facility discharge. These activities that mothers consigned a lot of time to include feeding, keeping the preterm baby warm, and hygiene and infection control among preterm babies.

Subtheme 1.1 Feeding was an overall challenge to mothers.

Feeding is a vital activity among infants. It is what determines the outcome of the baby. All mothers of preterm babies confirmed that feeding plays a major role in caring for infants and agreed that feeding preterm is a special task compared to term babies, and described feeding preterm as equally as a full-time job, whether breastfeeding, cup feeding, or tube feeding. Some mothers loudly noted waking up more than five times at night to breastfeed the baby.

“I was told by the health worker to breastfeed every 2 hours, my dear it is very hectic because after breastfeeding, I have to express breast milk and top up using the cup or a big syringe that they gave me to use and it’s hard for me to tell whether the baby is satisfied or not and that’s what I go through every day, maybe the full-time job you get weekends and rest”. Mother PFD 19

“Imagine breastfeeding and expressing milk for two babies, its worse at night when ‘Waiswa’ (first male twin) wakes up and you feed him, when you put your head down

to rest in just like 5 minutes ‘Tenywa’ (second male twin) also wakes up and you have to feed him too”. MOTHER PFD 3

“A week after discharge, my baby refused to feed even when I expressed. So, I had to take her back to the special care unit, and the health worker inserted a feeding tube again because my baby was not able to feed by mouth. The baby did not like the tube. After three days, she pulled it out. I had to go back to the hospital to insert it again”.

Mother PFD 1

Furthermore, some mothers declared how they wished to exclusively breastfeed their infants, but it was not possible because they could not produce enough breast milk. Other preterm mothers were not able to suckle properly to let milk out of the breast, and mothers introduced cow milk to the preterm less than six months.

“Feeding has been a challenge because the baby was not able to feed on its own. I did a lot of expression of milk at some point and resorted to cow milk and other soluble food, yet I was told to breastfeed for the first six months and then start other foods”.

Mother PFD 2

Subtheme 1.2 Keeping the preterm baby warm

Mothers demonstrated how they managed to keep their babies warm using Kangaroo Mother Care (KMC). It is a great method to keep preterm babies warm at home without equipment like infant warmers. Mothers revealed that KMC gives their baby skin-to-skin contact that helps the baby gain weight. In addition, some mothers disclosed how they kept their preterm babies warm other than KMC, for example, by igniting a charcoal stove locally known as ‘sigili’, surrounding the preterm babies with small jerry cans of

warm water. Below are the ways mothers provide warmth to their preterm babies at home.

“I was very committed to doing Kangaroo because I wanted my baby to be well, to get better, you know, when you do not do the baby does not gain weight. So, I was told when you do KMC a lot, the baby gains weight, and I had to do it with seriousness because I wanted my baby to gain weight”. Mother PFD 17.

“I do almost half a night when I go to sleep, I first put him until I wake up, like you know in the middle of the night, I get him off then in the morning when I wake up, put him again then around midday like that”. Mother PFD 4

“I stay in a water-logged zone, and our house is very cold, and it’s worse when it rains. So, I used to take the baby to the bedroom, and I put the charcoal stove in the sitting room, and the house got some warmth. Sometimes I used to boil water and put it in five-litre jerry cans, use them to surround the baby’s bed and keep close observation”.

PFD_FDG 1

In addition, mothers articulated the difficulties they went through while performing KMC, such as chest pain and backache, their babies became so weak, and it was cumbersome to the mothers who delivered through cesarean section.

I faced a challenge with KMC because of the chest and back pain, it began during the hospital admission but I had to force myself to do it in front of the health workers but at home, it became serious trouble for me I couldn’t handle it, because I was suffocating and coughing a lot.” Mother PFD 3

“KMC hurt my child because whenever I put him into my chest, a few minutes later, his body entirely became weak, and due to that circumstance, I stopped KMC.” Mother PFD_FDG 2

Subtheme 1.3 Hygiene and infection prevention.

Mothers demonstrated similar ways of maintaining their homes with proper hygiene as the best practice to prevent infections among preterm babies. Most of the mothers kept their preterm babies indoors and away from the visiting members of the community and hand-washed them before touching the baby. However, mothers noted the challenges they faced in fulfilling this task; for example, not bathing the baby but only wiping until approval was granted from the health workers. For mothers with older children, it was hard to control them from accessing their little siblings. Visitors also accused the mother of discriminating against them because they didn't allow them to touch and see the preterm.

“I have children here and they like their siblings, sneak into the room and play with the baby, some have flu and cough, which they get from school, and that puts my baby in danger.” PFD_FDG3

“Some people take it in a bad way when I tell them they cannot see my baby,”
Mother PFD 11

“Imagine having a baby close to two months after birth, who has not taken a bath”,
mother PFD 8

4.2.2 Theme 2: Financial Challenges.

The majority of the mothers highlighted the financial challenges involved in caring for preterm infants. Some mothers described how they sold some of their valuable properties to secure good health care for their preterm infants. However, they had to forego some recommended medicines and preemie feeding formula because they couldn't afford them.

Subtheme 2.1 High cost of medicines and formulas

The majority of the mothers expressed high costs of medicines recommended by the doctors to their preterm babies. For instance, syrups like Jusdee, Hemoforte, and Grovit. Some mothers described that the formula for feeding was very expensive. For example, the NAN preemie formula is very expensive.

“Milk for these babies costs between 50000 to 70000 Ugandan shillings, especially the NAN1 milk. So, I bought one tin when it got finished, I started giving classic milk because it is affordable.” Mother PFD 26.

Some mothers revealed that they were not able to secure all the recommended medicines for their babies because they couldn't afford to buy them all at once. So, they bought the cheapest ones and had to forego others.

“I was told to buy three different types of syrups for my baby, but didn't have the money to buy them all at once. So, I bought one at a time, and when it got finished, I bought another type, yet I was to give all at once.” Mother PFD 17

Subtheme 2.2 Transport costs.

Most of the mothers mentioned the issue of transport costs being a challenge to them. Preterm babies are followed up from the hospital on clinic days and mothers have to travel from the community to the health facility depending on the appointment date. Some mothers live far from Jinja Regional Referral Hospital and claimed that they were spending highly on transport fares to and from the hospital.

“They tell you the day to visit the hospital and, on that day, you find out that there is no money for transport and our boda charges around shs 30,000 to and from the health facility because he has to wait for you to receive services since you can’t use others from town because it’s far. PFD_FDG3

4.3 The perceived influence of post-facility discharge challenges on the psychosocial well-being of mothers with preterm babies

4.3.1 Theme 3: Mothers perceived their babies as medically vulnerable.

Mothers considered the use of different types of medicine for their preterm babies, which is not common in term babies and thus described their preterm babies as medically vulnerable, which worried them. Some mothers disclosed that they are not sure if their preterm babies will live longer; they believe any time their babies might die.

Subtheme 3.1 Medically ill

Some mothers described how their babies have suffered different medical conditions, that is to say, yellowish skin/jaundice, endless nasal congestion, the softness of the

head, anaemia of prematurity, and difficulties in breathing(asphyxia). Below are descriptions of what mothers are going through.

“My child got a name from my husband, he always asked me, How is your yellow baby girl because in the first month at home, the baby turned yellow thrice, and Nalufenya Children’s Hospital was like our home. A few weeks later, she became critically ill and was readmitted, and this time it was anaemia of prematurity.” Mother PFD 9

“You know that preterm babies require frequent monitoring. When the baby was struggling to breathe, I moved quickly to the hospital, and the baby was put on oxygen immediately for like 8 hours, and we stayed for three nights in the hospital receiving treatment”. Mother PFD 26

Furthermore, we found some outliers of preterm-born with congenital anomalies. The caregivers were worried. A mother presented medical forms, and the baby was diagnosed with clubfoot.

“He was born with a problem where his feet are not normal like other children. We have hope that the Cure Hospital doctors will treat him.” Mother PFD 10

Subtheme 3.2: Not growing well and small size.

Mothers expressed concerns about their preterm babies’ growth and revealed that they are not gaining weight, have smaller body parts, are delayed in bubbling, crawling, sitting, turning positions, and cannot hold a bottle to feed themselves.

“I feel my baby is not growing well, as if there is something the baby is missing that was not given while at the health facility receiving care. See, his legs are not equal.

If I don't turn him, he can spend the whole day in one position, but he's four months old." Mother PFD 2

4.3.2 Theme: 4 Mothers' health and psycho-social wellbeing.

This theme discussed how the mothers' physical, psychological, and social health was affected as a result of caring for preterm babies during the post-facility discharge.

Subtheme 4.1 Psychological distress

Most of the mothers caring for preterm babies expressed how they felt unpleasant feelings, which affected their lives. Mothers noted that they were experiencing episodes of sadness and anxiety because of the nature of the babies they were caring for. Some mothers mentioned feeling disempowered because of caring for babies who were not progressing in growth.

"I still live in fear because I don't know if this baby will grow. It appears like there is something she is lacking.

Since the day I gave birth to this baby. I am very worried because she is not growing like other babies, at least mothers whose babies are ok, but mine is the smallest among all the babies who are here today." Mother PFD 22

Subtheme 4.2 Sleep deprivation

All mothers mentioned having experienced short cycles of sleep. Mothers were never fully rested because of the number of activities to do with the baby such as KMC, feeding, and juggling with household chores. This was worse for the mothers with multiple babies.

“Ever since I gave birth right from the hospital, I have never got enough rest. I wake up not less than 5 times to feed the baby, and during that time, I am doing KMC and other household activities.” Mother PFD 19.

“I have twins, and the funny thing is that they rarely sleep at the same time. So, when you are planning to sleep, Waiswa wakes up, and when Waiswa falls asleep, Tenywa wakes, and that is the kind of life I am going through day and night.” Mother PFD 1 and 3

Subtheme 4.3 Social -Isolation and Relationship with Others

The new responsibilities of caring for the preterm infants made it difficult for the mothers to maintain social connections. Some mothers are noted as hiding from the public because of their appearance and the size of their babies.

“I look like a mad person I have little time to take proper care of myself like plaiting and working on my nails” Mother PFD 16

4.4 The support mothers caring for preterm babies received to cope with the post-facility challenges.

4.4.1 Theme 5: Social support.

Under this theme, mothers described the kind of social support they received during the post-facility discharge, and they also revealed how this kind of support restored their lost hope and empowered them to provide care to preterm infants while at home.

Subtheme 5.1 Emotional support

Mothers expressed how their friends, family members, and relatives showed them love, care, compassion, and encouragement, which helped them to cope with post-facility discharge challenges or experiences and emotions. Mothers noted that their friends and spouses were loving and empathetic during the moments when they felt low moods, lonely, and challenged. Mothers identified best friends as their true source of emotional support.

“My friends always come around on weekends, and they encouraged me to stay strong and concentrate on providing good care to the baby.” Mother PFD 13

Subtheme 5.2 Instrumental support

Mothers acknowledged that they received tangible assistance, like financial assistance, transport to meet clinic visits, bedding for the baby, and food items. The main source of instrumental support came from the spouse, neighbors, and friends.

“I received financial support from my friends. Some came with items for the baby like pampers, clothes, and basins.” Mother PFD 1

“My in-laws brought us food items from the village. Plus, my husband settles all our financial needs of transport and medicines.” PFD_FDG3

Some mothers revealed that they received support from relatives because they assisted in doing laundry for the mother and the baby and helped in cooking meals, especially the mothers who had a short-term physical limitation, such as mothers delivered through a cesarean section.

“Right from the hospital, my sister came around to support me to do the washing, and after discharge from the special care unit, she stayed with us and helped to do the cooking and laundry for my children and the people in our household.” Mother PFD 1

Subtheme 5.3 Informational support

Mothers revealed how they were supported by the health workers. This happened during the post-facility discharge clinic visits or follow-up visits at the hospital. Mothers noted the advice from health workers on infection prevention, good feeding, and following the immunization schedules.

“You know these babies are complicated, they present uncommon signs in the infants, but the good thing is that I have phone contact with the health worker, on several occasions, I called them to ask for guidance though most of the time they ended up telling me to take to the baby to the health facility for proper checkup.” Mother PFD

2

Some mothers pointed out the information and suggestions from the peer mothers on what has worked for them. The information they received from peers was on feeding. Furthermore, some mothers revealed using the internet to get information on the proper ways of caring for preterm infants.

“There are a lot of important videos on the YouTube channel which I follow, actually, those are specialists from countries with good health care systems like the USA and Canada. They provided me with a lot of knowledge that has helped me to have this baby grow well.” Mother PFD 29

CHAPTER FIVE

DISCUSSION

This study first explored the post-facility discharge challenges faced by caregivers of preterm babies, and these were feeding, keeping the baby, infection prevention, medical vulnerability, and financial challenges. This study also explored challenges to the psycho-social well-being of mothers caring for preterm babies, and the findings showed that mothers had psychosocial challenges these including psychological distress, relationship with others, social isolation, and sleep deprivation. Furthermore, this study identified the social support to the caregivers of preterm babies in the study area, and primary support was instrumental support.

Caring for preterm babies during the post-facility discharge is contrary to the assurance given to the mothers by the health practitioners that everything will be well at home. All mothers with preterm babies had a challenge related to caring for the preterm infants, which was so difficult for them to manage due to fear and worry about managing their preterm outside the hospital setting. The findings of the study are consistent with the previous research on challenges and social support.

In addition, some PFD challenges that happened are due to institutional gaps, including weight at the discharge of preterm below 2000 grams and before the 'expected date of delivery'(EDD), which is contrary to preterm care guidelines (World Health Organization, 2022) and not developing verbal and written discharge plan. Some did not have written notes on what to do to ensure effective care at home. Some mothers were not ready to manage preterm babies at home and needed to stay at the health

facility for some time. Other researchers argued that there is less emphasis on transitions from hospital to home-based care after discharge (Nalwadda et al., 2023)

Based on the study findings, the post-facility discharge challenges appear to be real in the home setting and have affected many mothers due to what mothers discussed as “round-the-clock care”. Mothers caring for preterm babies at home are in a dilemma of providing effective care to their infants, which is so demanding. For instance, feeding of different methods such as direct on the breast, expressing breast milk, cup, and tube feeding. Based on the findings of this study and the literature, the feeding difficulties in preterm infants appear to be universally shared. Therefore, the study findings were in agreement with the study conducted (Garti et al., 2021; Premji et al., 2017b; Sakyi et al., 2020).

However, findings showed that some mothers introduced other feeds at an early stage of care without the recommendations from the health workers, according to the WHO and Ugandan policy guidelines on infant and young child feeding. (Ministry of Health, 2009; WHO & UNICEF, 2003). This Emphasizes that infants should be fed on breast milk exclusively for six months of life and continue up to two years and beyond, unless medically contraindicated, and the mothers should be advised on ways to increase breast milk and decrease supplements or other fluids.

Effective care for preterm infants doesn't stop with feeding but is comprised of keeping the baby warm/KMC which was also a huge challenge to most of the mothers, in that mothers had no support to help to do the KMC it resulted in chest and backache and mothers called it off and introduced lighting of the charcoal stove or use of an

electric coil to keep the room warm. The study findings were in agreement with the study conducted by (Jamali et al., 2019; Kwesiga et al., 2022). However, there was a knowledge gap as to when to initiate, the number of times to perform KMC per day, and when to terminate it, because some mothers preferred to do KMC while taking a sleep, which is a dangerous practice.

The findings showed that infection prevention measures were misunderstood and some mothers regarded it as defiant to the cultural values of the family regarding newborns in a home. Previous studies revealed that (Buys & Gerber, 2021b), mothers found it challenging to control visitors and in-laws from having direct access to the preterm infant.

Based on the findings, many of the mothers revealed that they had financial challenges, which led to ineffective care towards their preterm babies. Mothers noted that the poverty in their household limited them from procuring essential medicines recommended by the pediatricians. Note a few outliers who missed immunization and follow-up clinic appointments due to a lack of transport.

Additionally, the findings revealed that most of the mothers mentioned have had psychological problems that were a result of caring for preterm infants at home. The existing literature showed that caring for preterm babies posed psychiatric conditions to the caregivers, such as anxiety and depression. (Buys & Gerber, 2021b; UDHS, 2022) Mothers articulated that they were experiencing stress, feeling disempowered, being nervous and anxious, and feeling depressed beyond the postpartum period.

Furthermore, mothers discussed how they lost social connection with friends because of the “Around-the-clock care” for preterm babies, and they could barely have time to hang out with their friends. Caring for multiple babies and juggling household chores was also another incident that made mothers lose social connections. Previous research (Garti et al., 2021) noted that some mothers found their interaction with other household members very hard because they judged them as being cursed to have a preterm baby, and this affected the mother’s self-esteem, and some chose to isolate themselves from family members.

All participants acknowledged having received social support in three ways: emotional, instrumental, and informational support. The most shared reliable source of social support was from the spouse. Though the spouses supported the mothers much in providing tangible materials and other household necessities, there was an outlier where one mother mentioned that her spouse assisted in performing kangaroo mother care because she delivered through cesarean section.

Additionally, friends and relatives were noted as the best source for emotional support, mothers revealed that they received words of encouragement that empowered them to stay strong. Some visited physically, and others reached out to them on phone calls. From the research (Brett et al., 2011; Lindberg et al., 2009; Lyne et al., 2022), it was discovered that informational support is very helpful in enhancing mothers’ strength and confidence. Furthermore, health workers, peer mothers, and health hub online channels were very helpful to the mothers during the post-facility discharge and were a good source of reliable information to improve care for preterm infants.

Based on the findings, Mothers lacked community-based peer-to-peer support groups and also community-based visits by public health professionals. According to the WHO guidelines to scale up post-facility discharge care of small babies, it's stated that during the post-facility discharge, mothers should have free access to health professionals for any type of counselling related to the care and support of their preterm and small babies and there should be a least one visit by the public health nurse to assess the home conditions ((Ministry of Health, 2009; WHO & UNICEF, 2003). In a multi-country study from Kenya, Ghana, Pakistan, India, and Uganda, researchers found that (Leahy-Warren et al., 2020; Lesley S. Taylor, 2016; Lomotey et al., 2020) linking a mother to mothers who previously had preterm baby experiences can provide effective assistance. However, the findings of this study discovered that no mothers were visited by the public health nurse or linked to the peer mothers.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

The post-facility discharge challenges are attributed negatively to the psycho-social well-being of mothers. Most of the mothers suffered psychological issues, including self-isolation and departing from social connections, sleep deprivation, and re-admission of the infants.

6.1.1 The challenges mothers encountered while caring for preterm babies during the post-facility discharge in Jinja district.

Caring for preterm infants at home is equivalent to a twenty-four-hour job, more so the feeding of preterm. All mothers universally shared feeding and thermal care/keeping the baby warm as the main challenges faced during the post-facility discharge. Other challenges were financial constraints, health, and the psychological well-being of mothers.

6.1.2 The perceived influence of post-facility discharge challenges on the psychosocial well-being of mothers caring for preterm babies in Jinja district.

In the hospital, mothers were sensitized about the nature of the baby they had and the proper care. According to the study findings, mothers perceived their babies as not normal children and as being medically vulnerable. Reasons included: performing kangaroo mother care, feeding of different methods like EBF, EBM, and tube feeding, giving their babies different syrups, and the babies were considered not to be growing well when compared to the term babies.

6.1.3 The support received by mothers to cope with the post-facility challenges in Jinja district.

The study findings provide valuable insights into the importance of supporting mothers caring for preterm to cope with post-facility discharge difficulties and improve the psycho-social welfare of mothers. The findings show that a community-based approach including peer-to-peer intervention can mitigate some of the common and avoidable post-facility discharge challenges.

6.2 Recommendations

6.2.1 To policymakers and researchers

Development of peer-to-peer intervention; mothers who have previously had experiences in caring for preterm babies can assist mothers in preventing some of the post-facility discharge difficulties.

Development of a communication strategy that directly targets behaviour change to encourage the community to embrace preterm birth. Sensitization of the community to accept that no visits to preterm babies is an infection prevention measure, but not disrespecting cultural values and norms. Engaging the community, Male involvement in the preterm is not disrespectful to men, but household-level support to the mothers for the better outcome of the preterm babies.

6.2.2 To Jinja Regional Referral Hospital.

There is a need for a holistic approach to deal with the post-facility discharge challenge, including training and equipping caregivers with the knowledge to manage

preterm babies at home, linking public health nurses in lower health facilities to visit mothers at home to assess standards of care at the household level. Additionally, a well-prepared facility discharge and mothers' knowledge of managing preterm babies at home determine the level post post-facility discharge difficulties and survival outcome of the preterm infants.

Equip and train the health workers to handle preterm issues in lower health facilities including Health Center III to handle minor complaints of mothers of preterm babies such as reinserting and changing the NGT / feeding tubes to reduce the burden of moving long distances and transport costs to the NICU at regional referrals.

Furthermore, there is a need for an active patient tracking system that notifies the lower health facilities of newly discharged preterm babies that are within the catchment area of the lower facilities.

6.2.3 To caregivers of preterm

The caregivers should follow the instructions given by the health workers; it will help to reduce the post-facility discharge challenges. The study findings indicate that mothers practiced certain activities on the preterm baby that are not recommended by the health workers, such as igniting the charcoal stove to generate warmth for the preterm baby, which is not the right practice in caring for preterm babies. Furthermore, there is a need to follow up with the immunization schedule.

6.3 Suggestion for further research

Lived experiences of mothers with functional disabilities caring for preterm babies during post-facility discharge.

Barriers and enablers for male involvement in practicing KMC during the post-facility discharge in rural Uganda.

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Appendix I: Consent form

UGANDA CHRISTIAN UNIVERSITY FACULTY OF PUBLIC HEALTH, NURSING AND MID-WIFELY

Information Sheet for Consent

Investigator

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The title of the proposed study

The post-facility discharge challenges on the Psycho-social well-being of mothers caring for preterm babies in Jinja Regional Referral Hospital.

Background and rationale of the study

Preterm birth is a global burden, with an estimated 15 million babies born before 37 weeks of gestation age and accounting for 11% of live births (WHO, 2018). Every year, close to 26,000 babies with prematurity complications in Uganda and between 11-28% mortality of preterm babies occurs during the post-facility discharge (UHNN, 2019). The efforts and initiatives are geared toward the babies and leave out the caregivers who play a big role in the baby's survival. This study aims to explore the challenges faced by caregivers of preterm babies and how they affect their psycho-social well-being, and the information generated shall be used to make possible recommendations to deal with the situation.

Purpose of the study

The purpose of this study is academic, and it intends to explore the challenges mothers face at home while caring for their preterm babies and how those challenges affect their psychosocial well-being. This study will involve interviewing caregivers whose

babies were discharged from the Jinja regional referral hospital neonatal unit but still receiving care on the clinic days' appointments.

Procedures: The study participants will be identified using the hospital records (neonatal register), targeting those who are expected on the clinic days. The researcher shall seek verbal consent, and after receiving services, they will obtain informed consent. they are expected to answer questions verbally using the interview guide, which shall be face-to-face and recorded, and the interview will not exceed twenty-five minutes.

Benefits: This study is for academic purposes, but it is expected to yield information that will be used by other researchers and stakeholders to make recommendations that will create better change in the area of maternal and child health.

Confidentiality and privacy; The interviews will take place in a private place within the health facility compound chosen by the participant, no participant will be interviewed in a group or a place where they feel uncomfortable. Sensitive personal identifiers of the participants (name, place of residence) shall not be captured. All information collected shall be kept in password-protected devices. However, the local research ethics committee may have access.

Question about participant rights.

In case you have any questions about your rights as a participant, you can reach out to Uganda Christian University accredited research ethics committee Mr. Osborn Ahimbisibwe 070442044/0775737627 email: ashimbisibwe@ucu.ac.ug; REC administrator, Dr. Peter Wasswa 0772405357 REC chairperson.

Ethical approval This study has been approved by an accredited ‘Research Ethics Committee’ (REC) based at Uganda Christian University.

Statement of voluntariness

Participation in this study is voluntary, you join at free will, the participation is not mandatory, and are free to decline. Also you have a right to withdraw from the study at any time without penalty.

Statement of consent

.....has described to me what is going to be done, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter the medical care the baby and I receive at the health facilities. In the use of this information, my identity will not be disclosed, I am aware that I may withdraw at any time. I understand that by signing this form, I don’t waive any of my rights but merely indicate that I have been informed about the study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name.....Signature/thumbprint of participant

Date

Name.....Signature of the interviewer/person obtaining informed consentDate.....

Namesignature of the witnessDate

Appendix ii: Interview guide

I am..... from Uganda Christian University Faculty of Public Health, Nursing, and Midwifery, conducting a study among mothers who delivered a year ago in Jinja Regional Referral Hospital. We would like to learn more about the challenges faced by mothers while caring for preterm babies at home. I would like to talk to the mother or anybody who was involved in providing frequent care to the baby(s). After identifying the right participant, ask if she is willing to participate. *(If you agree to participate, thank the participant and ask if you could through the consent form before any further discussion. If consent is obtained, start the interview, and if no consent is obtained, thank the participant and leave.)*

General information about the mother and their baby

1. Age of mother at birth
2. Marital status? a. single b. married
3. Parity.
4. Mode of delivery a. SVD b. C-section c. breach
5. Gestational age (weeks)
6. Number of babies delivered a. single b. twins c. triplites
7. Birth weight? (grams)
8. Lengthy stay at the health facility
9. Place of birth? a. Home. b. Health facility c. TBA

B. Let us talk about caring for a baby and the challenges encountered while at home after discharge from the health facility.

1. How was the condition of your baby after discharge?
2. What were you told to do at discharge to ensure proper care for the baby?
3. Can you describe the care you have been giving the baby while at home?
4. What areas of care did you find difficult for you to perform while at home?
Probe (KMC, cord care, breastfeeding, infection control, hygiene, and medicine).
5. How did caring for the baby affect your other daily income-generating activities *(probe if stopped working?)*
6. When all this happened, how did you feel toward yourself?
7. How did people in your household treat you when you returned home with the preterm?
8. How did the community react towards your baby?
9. What kind of circumstance that you and the baby face that required a medical concern? *Probe if the baby has ever fallen sick while at home, whatever the signs and symptoms. Did you seek care, from where, and who made the decision?)*
10. What challenges did you face while meeting the follow-up clinic day appointments?
11. How did you manage to overcome the challenges you mentioned earlier?
12. Any support received How? And by who? *(Probe if any support from spouse, relative, peer-to-peer, expert, friend, VHT, CSOs, etc.)*
13. Is there any comment you wish to make?

Thank you for participating

Consent form

The title of the proposed study

Okusoomosebwa ku mbeera ey'ebyo bwongo ba maama abazaire abaana nga bakaali kutuuka kuzaalibwa kwe babiitamu nga bamaze okusibulwa okuva mu ilwaliro mu Idhinda disturikiti.

Background and rationale of the study

Abaana okuzalibwa nga bakaali kutuuka kusomoozebwa muni yoona yoona, eera nga omuwendo gukununkiriza mu baana obukaire 15 nga bakaali kuweza ewiiki 37 eera nga ekyo kibalilwa ebitundu 11% ku abo abazalibwa nga balamu (WHO, 2018). Buli mwaka, abaana bakununkiriza okuwera 26,000 abalina okusimoozebwa okuvira ku kuzalibwa nga abakaali kutuuka mu Uganda eera wagati w'ebitundu 11% ne 28% ku bazalibwa nga bakaali kutuuka baffle nga bamaze okusibulwa okuva ku ilwaliro okwiira waka (UHNN,2019). Buliido okufiibwa ku n'eisira liteebwa kubaweere aye aate ba maama ba loba kufiibwa ku aate nga bakola kinene ino ku kubaawo kwa baweere. Okunonereza kuno kuluubirirwa okulaga okusomoozebwa ba maama abalabirira abaana abazaliibwa nga bakaali kutuuka kwebabitamu era n'engeri bwe bakosebwamu mu mbeera yo bwongo bwaibwe era nga okunonereza kuno kwa kuyamba okumalawo ensibuko ey'ebizibu eby'esambo dhino.

Purpose of the study

Ekgendererwa ekyo kunonenkereza kuno kya bya kusoma, era kugenderera okwetolola ebisoomoza ba maama bye babitamu waka nga balabirira abaana baibwe abazaliibwa nga bakaali kutuuka era n'egeri okusomoozebwa kuno je kubakosaamu ebyo bulamu bwaibwe ebyo bwongo. Kuno okunonereza kwiidha kubamu okubuuza ba maama abalabirira abaana ebibuuzo okusingira irala abaana abasibulwa okuva mw'ilwaliro eikulu ery'Eidhinda webalabiririra abweere aye nga baira yo okufuna obwidhandhabi nga baviira ghaka.

Procedures

Abajja okwenigira mukunoonekereza kuno ba kulodebwa nga tweyambisa ebiwadiko eby'Eilwaliro nga eisira liri kw'abo abaida okulwala ku nnaku d'eilwaliro. Omunonereza aidha kwogeraku nhi gwasubira okubuuza ebibuuzo nga asooka kumusaba lukusa ghalala no kumutegeeza ebibuuzo ne ngeri je bisuubirwa okwiriibwamu. Okubuuzibwa ebibuuzi ti kwida kumala ibanga liswika dakika amakumi abiri na itaanu era nga kwa luwayo wabula ti kuwandiika, naire nga kunabamu okugema amaloboozi kutaambi.

Benefits

Ekgendererwa ekyo kunonereza kuno kya bya misomo era nga ku subirwa okuvamu obubaka obunakozesebwa aba nonereza abanda ghalala ni bekigemaku okusobola okukola enteekateeka eyo kutereezza ebyo bulamu byaba ba maama abalinda ghalala ne byo bulamu bya baana.

Confidentiality and privacy.

Oluwayo olw'okwiramumu ebibuuzo lwa kuba mu kifo ekyekusifu ekitali kya lukale mu ilwaliro ekinalondebwa era nga kinasalibwawo oyo aikiriza okwenigira mu luwayo luno, wazira muntu yeena yeena anabuzibwanga bibuuzo nga ali mu kinsu ky'abantu oba mukifo kyatawuliriramu

milaala. Ebyekusifu ebigema ku muntu (nga amaina, n'ekifo ya sula) tibida kuwandikibwa oba oku twalibwa. Obubaka bwona bwona obunasololezebwa bwidha kukumibwa ku masimu n'ebyuma bikalimagezi ebitamalaga gakozezebwa buli omu, aye ab'akakiiko akatwala okunoonereza bo bayinza okufuna obubaka buno.

Questions about participants' rights.

Bwoba n'ebibuuzo ku idembe lyo nga eyenigire mu kunoonereza kuno, osoboola okutukurira akakiiko ak'ebyempisa mu by'okunoneereza aka Uganda Christian University Mr. Osborn Ahimbisibwe 070442044/0775737627 email: ashimbisibwe@ucu.ac.ug ;REC administrator, Dr. peter Wasswa 0772405357 REC chairperson

Ethical approval

Kuno okunoonereza kwakakasibwa era kulungamizibwa akakiiko ak'byempisa mu kunoonereza akasinzirira ku Uganda Christian University.

Statement of Voluntariness

Okwenigira mu kunonereza kuno kwa kweyendera, era tikwabukake n'olwekyo omuntu asobola okuloba okwenigiramu oba okubivaamu awazira kunenezebwa naire okuvunanizibwa.

Statement of consent

..... aninonoire ekijja okukolebwa, emiganulo ejikirimu ghalala n'eidembe lyange ku kigema kukwenigira mukunonerezebwa kuno. Ntegeire nti okusalawo okwenigira mu kunoneraza kuno ti kwiida kukosa oba okukyusa endabirira n'obwidandabi bwange ghalala no bw'omwana wange bwetuffuna wano ku ilwaliro. Mukukozesa obubaka obuva mu kunonereza kuno, ebingemaku tibiidha kukozezebwa, nkiidi nti wenendera wona wona okubivaamu nsobola okuvaamu. Ndhidi nti nga nta omukono ku kiwandiko kino, ti tolebwaku idembe lyange wabula kiraga nti ntegezeibwa ku kunoneeraza kwe ndi kwikiriza enigiramu.

Ekiwandiko kino kidda kumpebwa ku zeena.

Erina omukono/ekinkumu
.....

Enaku d'omwezi

Erinaomukono/ekinkumu ky'omunonereza alikunonya olukusa okufuna obubaka

Enaku d'omwezi

Appendix ii: interview guide.

Ninze okuva ku Uganda Christian University oluuyi olugemagana ku by'obulamu eby'olukale, abasawo na bazaalisa nga ndi kunonenkereza ku ba maama abazaala omwaka oguweire mu Ilwaliro eikulu ery'Eidhinda. Twenda ku manha ebisomozebya ba maama bye baabitamu waka nga balabirira abaana bazaliibwa mga bakali kutuuka. Nenda kuwayaamu ni maama oba omuntu yeena yeena ayehingira mu ndabirira ya baana bano. Oluva inhuma lw'okuna omuntu atuukana okwenhigira ku kunonenkereza kuno, mubuuze oba eyenda okwenhigira mu. (*bw'aikiriza , mwebaze era omubuuze oba asobola okwiduzaamu ekighandiiko ekiraga nti aikiriza . bwamaliriza okwikiriza mu buwandiike oba nibwaba nga t'aikiriza, mwebaze are oveewo oje*)

A. General information about the mother and their baby

1. Emyaka gya maama weyazaliira
2. Mufumbo oba mbe? a. Timufumbo b. Mufumbo
3. Okufanagana
4. Yazaala atya a. Yazaala bulungi b. Yalongosebwa
5. Enda yali ya ibanga ki(wiiki imeka)
6. Baana bameka abazaalibwa a. Mulala b. Irongo lye Babiiri c. Irongo lye Basatu
7. Obuzito bwo mwana mu kuzaalibwa (kiro imeka)
8. Ekiffo mwe yazaalibwa? a. Waka b. ku ilwaliro c. ewa mulerwa

B. Let us talk about caring for the baby and the challenges encountered while at home after discharge from the health facility.

1. Embeera y'omwana wo yaali etya bwe babasibulira?
2. Biki bye bakukoba kungeri enungi edho kulabiriramu omwana wo?
3. Biki ebya kukalubira einu mu engeri edho kulabirira mu omwana bwe ghali waka? Gobereera (KMC, okulabirira akaleera, okwonsa, okutangira obuwaire walala n'obuyondo, eidagala)
4. Okulabirira omwana wo kwakosa kutya entabuza yemirimu gyo naddala egireta esente (Buuza oba yalekera okukola)?
5. Bino byona byona bwebya tuuka wo, wawuulira otya yee kumbeera yo?
6. Abantu abomumaka go bakubisa batya bwe waira waka n'omwana eyazaalibwa ng'akaali kutuuka?
7. Ab'okukyaalo b'ebiisa batya eri omwana wo?
8. Mbeera ki ighe oba omwana wo gye yabitamu nga yetaaga okukolebwa ku abasawo?
9. Kusomozebwaki kwe wafuna mukuba ng'otuukiriza enaku edhateebwa wo odhokwiira ku ilwaliro okubonanga abasawo.
10. Ebisomooza ebyo waigulu wabibitamu otya ?
11. Ghaliwo ekindi ky'oyenda okwongeraku okunkoberaku?

Thank you for participating

Appendix iii
a. REC clearance



**UGANDA CHRISTIAN
UNIVERSITY**

A Centre of Excellence in the Heart of Africa

03/08/2023

To: Pascal Kiweewa

+256706019156

Type: Initial Review

Re: UCUREC-2023-541: THE POST –FACILITY DISCHARGE CHALLENGES ON THE PSYCHO-SOCIAL WELL-BEING OF MOTHER CARING FOR PRETERM BABIES IN JINJA DISTRICT

I am pleased to inform you that the Uganda Christian University REC, through expedited review held on **17/07/2023** approved the above referenced study.

Approval of the research is for the period of **03/08/2023** to **03/08/2024**.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **03/08/2024** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Uganda Christian University REC:

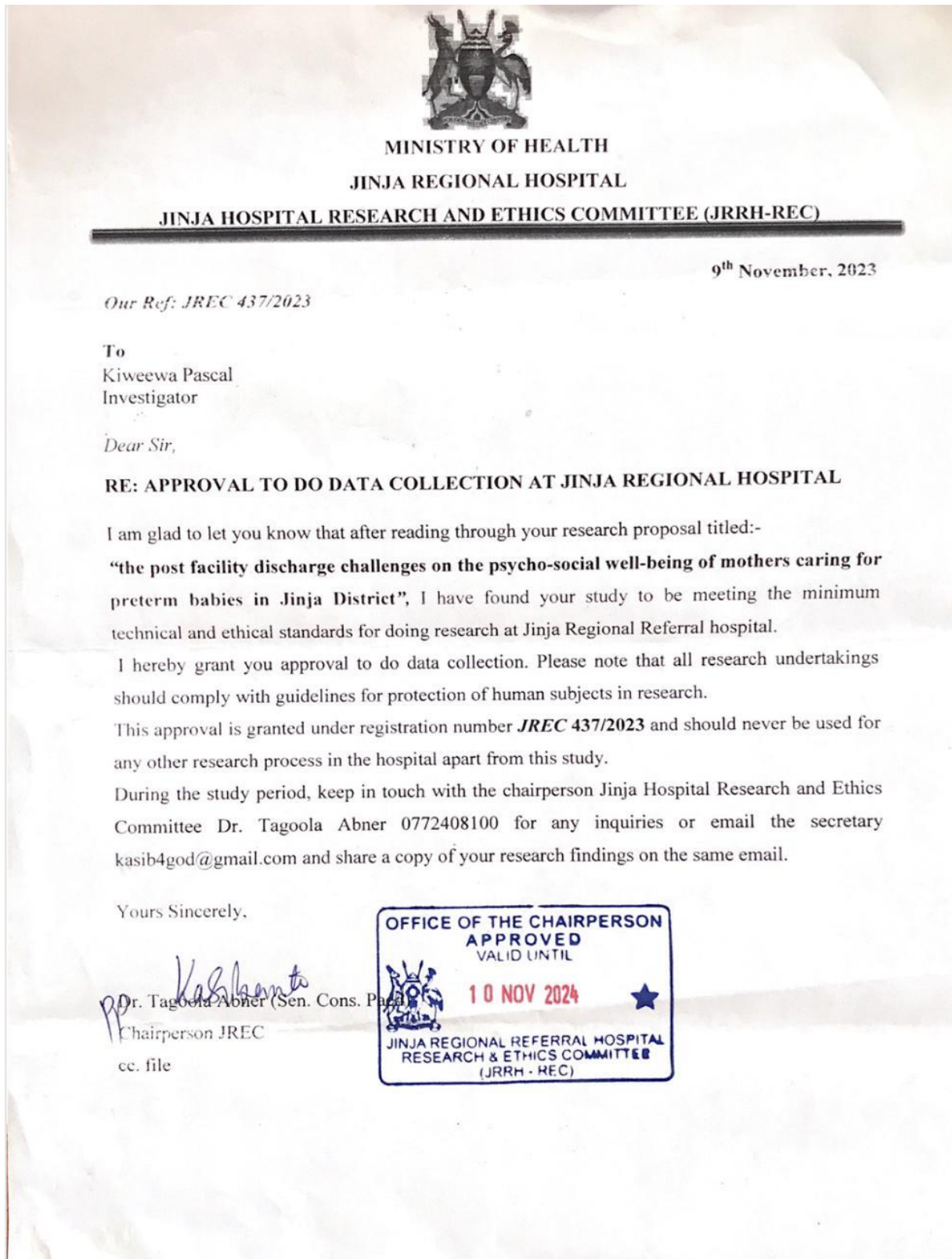
No.	Document Title	Language	Version Number	Version Date
1	Data collection tools	English and lugoga	V1	2023-05-31
2	Protocol	English	V1	2023-05-31

Yours Sincerely



Prof. Peter Waiswa
For: Uganda Christian University REC

b. Approval letter by Jinja hospital





UGANDA CHRISTIAN UNIVERSITY

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UGANDA CHRISTIAN UNIVERSITY
SCHOOL OF RESEARCH & POSTGRADUATE STUDIES
DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)

Date: 08/04/2025.....

Name of Candidate: KIWEEWA PASCAL..... Reg. No:RS21M07/011.....

Title of Dissertation: “The post-facility discharge challenges on the psycho-social well-being of mothers caring for preterm babies in Jinja Regional Referral Hospital”

SN	COMMENTS BY EXTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	Grammar and typos	Proofreading and Grammar Guide Book	Reduced syntax and grammar errors.
2	Objectives should reflect a qualitative nature	Stated to reflect the qualitative nature of the study	Objectives are rewritten with improved verb usage, demonstrating clearer intentions and outcomes
3	The candidate should have an operational definition of key terms, e.g. caregiver, premature, etc.	Provided a clear operational definition for key terms, including premature, post facility discharge, etc, to ensure precision and consistency.	Well-defined operational definitions in the preliminary pages

4	The candidate should describe how the sample size considerations for the Key in-depth and focus group were determined, how and who conducted the interview and their qualification, where the interviews with the caretakers took place. The language in which the interviews were conducted, and if there was a need for translation of the interviews and who did this? Who carried out the data analysis, and if there was a need for the service of a social scientist?	Included in the methodology	Appendix of translated (Lusoga) information sheet.
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SN	COMMENTS BY INTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	The language is weak with many syntax and grammar weaknesses	Proofreading and phrases	Reduced syntax and grammar errors.
2	Data was collected only in Jinja RRH, but the title talks about Jinja District. These two are different. The scope was certainly limited to Jinja RRH!	Clearfield the scope and setting of the study to ensure consistency between data collection and reporting, specifying that findings apply to Jinja RRH rather than Jinja district.	The study reports accurately reflect the scope and setting of the research.
3	Analysis needs to be documented better!!	Documented detailed analysis steps to ensure transparency	Analysis documentation is thorough, clear and supports the validity of the findings.
4	Please summarize your literature in a paragraph at the end, and write the summary in such a way that it communicates the knowledge gap!	Include a section on a summary of the literature	Literature review concludes with a clear summary that effectively communicates the

			knowledge gap, setting the stage for the research study
--	--	--	---

N	COMMENTS BY VIVA VOCE PANNEL	ACTION TAKEN	INDICATOR
1	Candidate advised to read hospital to home paper by Adara to enrich the study	Reviewed the paper and incorporated relevant insights	Contributing to more research outcomes.
2	Clarify quality control aspects	Read the book by Criswell,	Data saturation
3	Include the definition of concepts	Included the operational definition key terms in the preliminary pages.	Well-defined operational definitions
4	To change the verbs used in the objectives	Revised objective to incorporate more qualitative verbs such as to explore and to understand.	Objectives are written with improved verb usage, demonstrating clearer intentions and outcomes
5	Make general corrections on grammar and typos	Proofreading and phrasing sentences.	Reduced syntax and grammar errors.

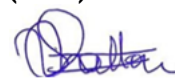
Kiweewa Pascal



Candidate's Name

Signature

Shallon Atuhaire (PhD)



Supervisor's Name: 05/05/2025

Signature