POST-DISCHARGE EXPERIENCES AMONG CAREGIVERS OF PRETERM BABIES IN KERICHO COUNTY, KENYA

ABIUTY OMWENGA OMWERI

A Thesis Submitted to the Institute of Postgraduate Studies of Kabarak University in Partial Fulfilment of the Requirements for the Award of Master of Medicine in Family Medicine Degree

KABARAK UNIVERSITY

NOVEMBER, 2024

DECLARATION

1. I do declare that:

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Abiuty Omwenga Omweri

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RECOMMENDATION

To the Institute of Postgraduate Studies

The thesis entitled **"Post-Discharge Experiences Among Caregivers of Preterm Babies in Kericho County, Kenya."**, and written by **Abiuty Omwenga Omweri** is presented to the Institute of Postgraduate Studies of Kabarak University. We have reviewed the thesis and recommend it be accepted in partial fulfilment of the requirement for the award of the degree of Master of Medicine in Family Medicine.

Signed:  Date:_____

Matthew Loftus,

Lecturer, School of Medicine and Health Sciences.

Kabarak University.

Signed:_____ Date:_____

Prof. Dr. Pamela Kimeto Ting'ei,

Dean, School of Medicine and Health Sciences

Kabarak University.

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DEDICATION

I dedicate this research proposal to the AIC Litein Mission and Kapkatet Sub-County Hospitals' paediatric departments and my Supervisors, Dr. Matthew Loftas and Dr. Pamela Kimeto Ting'ei in recognition of their unconditional support throughout this academic task.

ABSTRACT

Worldwide, at least 15 million preterm babies are born yearly, of which 1 million succumb to complications directly related to premature birth. Premature birth is defined as a gestational age of less than thirty-seven weeks. Sub-Saharan Africa and Asia contribute up to about 60% of the world's preterm births with the highest mortality rate worldwide for children aged between 0 to 5 years old. In Kenya, the prevalence of preterm birth in Kenyatta National Hospital is 18.3% while the mortality rate of preterm babies under 5 years is about 7% per year countrywide. This study aimed at understanding the experiences caregivers of preterm babies face at home in the first 6 months post-discharge. This was a phenomenological study. Sixteen preterm caregivers were interviewed using a semi-structured questionnaire at the participants' convenient place. This was after purposeful homogeneity sampling was done at A.I.C Litein Mission and Kapkatet County hospitals' outpatient clinics. Data was audiotaped then transcribed into hard copies and lastly analysed into relevant themes. The age of the caregivers ranged from 25 to 42 years old and their mean was 34. The gestational age of the babies at birth ranged between 26 to 32 weeks, their birth weight was between 900 grams to 1900 grams, and their hospital stay was 7 to 90 days. 100% of the caregivers had formal education. 87.5% were married while 12.5% were single mothers. The following themes were explicitly articulated: Post-discharge experiences, Support given to caregivers, and Expectations of caregivers. The findings showed that caregivers face a range of challenges that include but are not limited to social isolation and stigmatization. Fathers were applauded for their psychosocial support. There is a need to amalgamate patient-oriented care with that of community-oriented care.

Keywords: *Preterm, Premature, Birth, Experiences, Caregivers*

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ABBREVIATIONS AND ACRONYMS

AIC:	African Inland Church
EDD:	Expected Date of Delivery
HIV/AIDS:	Human Immuno-deficiency Virus/Acquired Immuno-deficiency Syndrome
KABUIREC:	Kabarak University Innovation and Outreach Research Ethics Committee
KMC:	Kangaroo Mother Care
NACOSTI:	National Commission for Science, Technology, and Innovation
NCU:	Neonatal Care Unit
PPD:	Post-Partum Depression
PTSD:	Post-Traumatic Stress Disorder
WHO:	World Health Organization

CONCEPTUAL AND OPERATIONAL DEFINITION OF TERMS

Caregivers: Someone responsible for taking care of another person (parents/ grandparents/relatives

Gross Congenital Anomalies: Severe structural or functional anomalies present before or at birth. They commonly involve heart defects, neural tube defects, and Down syndrome.

Kangaroo Mother Care: Care given to the baby by the mother through the skin to skin contact

Parent(s): Biological mother/ father

Preterm/Premature Babies: Defined as babies born before completed 37 weeks of gestational age.

Preterm Birth: Birth before completed 37 weeks of gestational age. Categorized into extremely preterm (< 28 weeks), very preterm (28 to 32 weeks), and moderate to late preterm (32 to 37 weeks).

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter includes the background of the problem, the statement of the problem, the justification of the study, the purpose of the study, research question, the objectives, the significance of the study, and the limitations of the study.

1.2 Background of the Problem

Every year, 15 million premature babies are born, out of which 1 million die due to complications directly related to prematurity (World Health Organization [WHO], 2018). Prematurity is defined as a gestational age of less than 37 weeks. 60 per cent of these preterm births occur in Sub-Saharan Africa and Asia translating to almost the same number of parents with preterm babies in these regions. Of note is that these preterm babies die due to preventable causes of which neonatal sepsis, hypothermia, birth asphyxia, and respiratory distress remain on top of the list (Olack et al., 2021). The mortality rate in less than 5 years old children in Sub-Saharan Africa and Asia is high compared to other regions in the world (WHO, 2018).

The mortality rate in Kenya for preterm babies is about 7% of the 193,000 preterm births per year (Kenya Profile of Preterm and Low Birth Weight Prevention and Care, 2019). There is a great need for professional support when transitioning preterm babies from hospital care to home care. This should be based on individual assessment of the parent's needs, like coping strategies, psycho-emotional state, stress levels, and socioeconomic status. This is essential to provide safe care and services post-discharge, which will be effective and efficient for both the parents and the preterm baby (Boykova, 2016). Mothers of extremely preterm infants suffer from anxiety, depression, and post-traumatic

stress disorder (PTSD) for longer periods than those with term babies (Fowler et al., 2019). The PTSD would be a result of the birth process itself, mother-child separation, the stress due to the procedures the babies have to undergo such as insertion of a nasogastric tube and intravenous access, long periods of being on oxygen supplement, and lack of enough sleep due to scheduled feeding overnight (Lasiuk et al., 2013;Guillaume et al., 2013). If the postpartum depression is not treated in time, the mother becomes less caring and worse still, insensitive to the preterm baby's needs (Slomian et al., 2019). In another study, mothers of preterm babies were found to have an increased risk of developing ill-health and negative feelings towards their babies in the early months of their lives (Henderson et al., 2016). Ill health includes depression in mothers which predisposes their children to inadequate breastfeeding, malnutrition, and eventually poor health (Dadi et al. 2020).

There is a great need for screening for mental illnesses in mothers of preterm babies to prevent the consequences on the mothers and their babies (Dadi et al. 2020). Since a majority of parents with preterm babies do not have the required skills and knowledge for caring for their babies making such care a challenge once out of the NCU, healthcare givers should equip the parents with the required skills and knowledge on how to care for their preterm babies not only in hospital setting but also at home. Religious and community leaders, together with health caregivers, provide physical and emotional support in taking care of the preterm babies as far as social norms and Kangaroo Mother Care (KMC) of these babies are concerned (Lydon et al., 2018).

This was also echoed by Adama et al. (2021) in their study that observed the importance of social-cultural practices which stated that child care is a communal responsibility. These social-cultural norms included respect for the support given by the elderly, therole

of traditional medicine in the treatment of sick preterm babies, and lastly the support given by the extended family and community at large. Several studies have been conducted in America, Europe and African countries like Ghana and Malawi (Adama et al., 2021; Henderson et. al., 2016; Lydon et al., 2018; Godwe et al., 2014) but such studies are scarce in Kenya, let alone Kericho County. This became of interest after a couple attending paediatric outpatient clinics on follow-up due to the prematurity of their baby told me "*Daktari hujui shida tunazo pitia nyumbani na huyu mtoto, nyinyi mnatungoja tu hapa kliniki*". Translated as "Doctor you don't understand the problems we have at home with this child, you only wait for us here in the clinic". Little is known about what goes on in the minds of these caregivers of preterm babies on the day of discharge and their life at home with the community as they take care of their babies in the absence of a health professional worker. Follow-up to their homes and communities post-discharge is unheard of in Kenya and specifically in Kericho County.

The only place and time these parents especially the mothers are met is during their follow-up visits at the outpatient paediatric clinic. In some instances, they miss clinic follow-ups and are never examined by medical professionals, or they come back when the babies are critically ill and the parent is depressed. Since there is no integration of the services provided in the hospital setting to those provided in the community specifically for parents of preterm babies, this study seeks to explore the challenges these caregivers face while at home.

1.3 Statement of the Problem

Due to the vulnerability of preterm babies, their care needs more skills, not only on the side of the health caregivers but also the parents and community at large. Much has been studied on how parents especially mothers of preterm babies are affected while in the newborn care unit (NCU) but less is known about what happens once they are discharged

from the NCU. Mothers of preterm babies feel disconnected from their babies, require empathy and constant communication concerning the health of their babies from the healthcare team, and want to be involved in the management of their vulnerable babies. At the same time, fathers also often feel denied the opportunity to be with their spouses and their preterm babies (Gallegos-Martínez et al., 2013). All these concerns will need to be addressed before they translate to anxiety, stress and depression while in the NCU and even after discharge. Once out of the NCU, there are no outlined protocols on their follow up to the community. Consequently, postpartum depression is often undiagnosed and not managed; meanwhile, preterm babies are often lost for follow up making it difficult to monitor their motor and cognitive growth. This study forms a basis for recommending the integration of services in the hospital setting to those offered in the community to reduce the mortality and morbidity of preterm babies.

1.4 Study Justification

To reduce the high mortality rate for children aged between zero to five years old, each country must take into consideration the main causes of death in this age group and apply the most appropriate preventive measures which will include patient-centred care. Apart from practising patient-centred care, there is a great need to go the extra mile for our health system to incorporate community-oriented care for our patients. There is need to have outlined structures in place giving direction on how preterm babies can be followed up to the community, keeping in mind that in Kenya, preterm birth is the second most frequent cause of all mortality after HIV/AIDS (Kenya Profile of Preterm and Low Birth Weight Prevention and Care, 2019). In Kenya, the health care system can only be effective and efficient in its totality if it integrates patient-centred care together with community-oriented care. While the preterm babies are admitted in the hospital, ideally patient-centred care is provided and should be used as a leeway to enter the community

after their discharge home. This qualitative study using phenomenological design, explored the experiences parents of preterm babies undergo while taking care of their preterm babies at home and gave recommendations on the importance of community-oriented care.

1.5 Purpose of the Study

1.5.1 General Objective of the Study

The purpose of this study was to explore the experiences caregivers of preterm babies face at home post-discharge from Litein AIC Mission Hospital and Kapkatet County Referral Hospital in Kericho County.

1.5.2 Specific Objectives of the Study

The following are the specific objectives of the study:

i. To explore caregivers' experiences in caring for their preterm babies at home during the first six months after discharge from NCU.

ii. To explore the support caregivers of preterm babies get from the community within the first 6 months' post-discharge from NCU.

iii. To understand the expectations caregivers of preterm babies have in terms of education and support during their hospital stay, at discharge and during follow-up visits at the clinics.

1.6 Significance of the Study

The findings of this study will be communicated to the relevant departmental heads of A.I.C Litein Mission Hospital and Kapkatet County Referral Hospital by the researcher who will in return inform the hospitals' administration. The hospital's administration will let the Ministry of Health in Kericho County know the findings and the

recommendations for it to take action where necessary. It will also inform the relevant institutions on the specific needs of parents of preterm babies once they are discharged home and give recommendations on the structures to be put in place for follow-up. The study will help to direct resources that will enable the follow-up of these clients to the villages and this in return will help reduce the deaths and morbidities related to prematurity in Kericho County.

1.7 Limitations of the Study

The findings of this study will not be wholly generalized in Kenya because of the diversity of the communities in Kenya and the catchment area where the study will be conducted. There will be need to conduct a country-wide study for it to be generalized. The two hospitals do give maternal services not only to the natives of their catchment area but also from other counties like Bomet and Kisii making it difficult for follow-up to their homes because of distance. This might limit the number that will be included in the study since the participants should be within Kericho County. To overcome this challenge, the researcher did have interviews conducted within the research centres for those participants willing to take part in the study but not coming from Kericho County. The study anticipated a language barrier however all the participants were well conversant with both English and Kiswahili languages during the interviews and this did not necessitate for an assistant.

This study cannot be generalized to the whole country since it was conducted in only one county. The information given might be limited due to the preference of the participant's choice of information to give and the psychological disturbances experienced.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter looks at the known knowledge of the challenges caregivers of preterm babies face at home after discharge. To understand the knowledge gap in the literature, the study had the literature review explored in line with the study objectives. The final section of this chapter will contain the conceptual framework of the study.

2.1.1 Caregiver Experiences at Home

The magnitude of psychosocial challenges parents of preterm babies face is of great interest not only while they are in the hospital, but also after they are discharged home with their babies. Slomian et al. (2019) concluded their study by saying that postpartum depression (PPD) experienced by mothers, negatively impacts the health of the mother and the preterm baby up to 3 years. The PPD creates an unfriendly environment for both the child and the mother. This, in turn, affects the preterm baby physically, mentally, socially, and psychologically. The study did emphasize that children in low-income countries suffer more than those in middle-income and high-income populations. Fowler et al. (2018) support the notion that mothers' psychosocial issues should be addressed amicably for them to be mentally stable and emotionally present for their extremely preterm babies. Parent-infant interactions are dependent on the stability of the mental and psychosocial status of the family. There is a need for early detection of any deviations in the mental health and psychosocial issues in the family to avoid the negative consequences that might follow (Purdy et al., 2015). Carson et al. (2015) added to the above in their conclusion that the probability of fathers and mothers of preterm babies developing post-partum depression is 2 times higher, compared to the parents of term

babies. Hoffenkamp et al. (2015) were of a different opinion that optimal parental care for their preterm babies which includes the psychosocial aspect was not so much connected to prematurity itself but to the parents' negative perspective and characteristics.

Due to broken health systems, lack of support, and stretched uncertainties, parents of preterm babies are pushed into psychological trauma. These mothers and fathers wonder exactly what their role is when it comes to taking care of a preterm baby-: for example, how to feed them, handle them to minimize their pain and suffering, and to what extent should they allow other family members to handle the premature child (Lasiuk et al., 2013).In Malawi, there is stigmatization of mothers with very low birth weight infants in the community calling for more resources to be channelled towards creating awareness in the community about preterm births and to reduce stigmatization (Koenraads et al., 2017). On the other hand, Gondwe et al. (2014) observed that poverty and lack of knowledge in the community negatively impacted the care of preterm children while at home. At the same time, Gondwe et al. (2014) found that mothers of preterm babies lacked time to do most of the household chores, businesses, and farming since they needed to be available for their babies. Men were assumed to have extramarital sex since they were not allowed to have sex with their wives who were nursing the preterm babies until they were cleansed traditionally.

This could not only lead to infidelity but also cause psychological trauma to women. On the other hand, Jerntorp et al., (2021) conducted their study in Sweden that highlighted the psychological trauma men also undergo when taking care of their preterm babies not only in the hospital setting but also at home. They said that fathers felt isolated from their families and as a result, they needed to be incorporated in taking care of the preterm baby together with the mother. There is a need to come up with social and financial programs

in the community to support families and parents of preterm babies (Lakshmanan et al., 2017). In Kenya, particularly Kericho County, no study has been conducted to understand the challenges parents of preterm babies face after discharge in the community. This study will be able to either affirm the above findings or make discoveries.

2.1.2 Community Support for Caregivers of Preterm Babies

Sub-Saharan Africa and Asia contribute the highest mortality rate worldwide for children under the age of 5 years (WHO, 2018). The process of giving birth in itself is traumatizing but to lose a baby is deeply painful to the parent. It is important to note that prematurity is considered to be the highest risk factor for high morbidity and mortality in the whole world. These consequences can be immediate or long-term. Feeding and nutritional requirements for premature babies remain the greatest challenge for not only the healthcare providers but also the parents. Once the baby has been discharged from the NCU, there are emotional concerns for the parents and the babies especially the first year of life (Baraldi et al., 2020). In addition to that, Ericson et al. (2017) showed that mothers felt strengthened and satisfied in breastfeeding their preterm babies through the continuity of care provided by the healthcare providers through calls and responding to the caregiver's calls while in the community.

Apart from the breastfeeding challenges addressed above, parents and families of preterm babies had financial constraints and felt to be socially isolated. This impacted them greatly, hence the need for financial and social support programs that are community-based (Lakshmanan et al., 2017). To ease the financial burdens and social isolation, the elderly in the community are accorded the responsibility of ensuring that the community participates in all aspects of taking care of the preterm babies and their

parents while at home. This support could include the provision of food, herbal medication, help with household work and financial support wherever possible (Adama et al. 2021). On the other hand, community health care nurses provide the necessary knowledge to the community on the needs of preterm babies and their parents.

For effective service delivery in the community, nurses need to be trained and have access to the information relevant to the care of not only preterm babies but also their families (Petty et al. 2021). Home care practices for preterm babies include cleanliness, breastfeeding, KMC for warmth, and seeking medical care when the need arises (Nabiwemba et al. 2014). There is a vast of information on the internet concerning the above aspects of preterm care but parents need guidance from health care givers on internet use to avoid being misguided leading to mismanagement of their preterm babies at home (Alderdice et al. 2018). Every one of the above support provided in the community will reduce the mortality and morbidity of preterm babies and at the same time improve the physical, emotional, psychological, and financial well-being of the parents of preterm babies too.

2.1.3 Expectations of Caregivers with Preterm Babies

Once a preterm baby has been born, he/she is admitted to the NCU and there is immediate separation from the mother. This creates anxiety and uneasiness in the mother since she is only allowed to visit and be with the baby following specific timelines provided and not at any time she would like to do so. Mothers' experiences while their babies are in the NCU have been discussed broadly but unfortunately very little is said after they are discharged home. On the other hand, fathers of preterm babies have been forgotten especially in the African setup where the role of taking care of the baby is left to the mothers. The same observation was made by Premji et al., (2019) who said that the

hospital system does not have mechanisms in place that prepare the fathers to take care of their late preterm infants. Also, Premji et al., (2019) did say that paternal care is equally important at the hospital and community levels. It has been shown that mothers of preterm babies, especially extremely preterm babies, undergo emotional and physical stress for a longer period compared to mothers of term babies (Fowler et al., 2019). In another study, Lomotey et al. (2019) concluded that good communication between the nurses and the mothers in the NCU does improve the physical and even psychological well-being of these mothers.

For these mothers to transition from hospital to home setting with their preterm babies confidently, there is a great need for healthcare professionals to prepare them by providing the necessary information so that they can have good mental health which is crucial for maternal care (Fowler et al., 2019). It was discovered by Lakshmanan et al. (2019) that for a smooth transition of parents with preterm babies from NCU to home care; families needed peer support, nursing care, and mobile health technology. Without good communication, these parents feel neglected, lonely, and burdened with the responsibilities of looking after their vulnerable preterm babies (Wigert et al., 2014).

It was noted by Boykova, (2016) that transition from hospital should be an individualized process because people have different capabilities of adjusting to new situations like physical, emotional, and psychological stresses. Unfortunately, there is no standard protocol for discharge making it hard to provide effective, efficient, and safe care services after discharge. In their study, Fleming et al. (2016) said that parents are not prepared for discharge since about 75% of preterm babies get discharged from NCU 2-3 weeks earlier than the expected time which is the expected date of delivery (EDD). They suggested the use of charts for approximating the expected date of discharge which in return will aid the parents' preparedness for discharge. Purdy et al. (2015) support

interdisciplinary teamwork in ensuring that there is a smooth transition from the NICU to the community. The multidisciplinary team helps the families of preterm babies by offering them counselling services in regard to mental and psychological health while in the hospital and after they have been released to their homes in the community.

In a research done by Bockli et al. (2014), they found out that NCU follow-up clinics have challenges, especially financial constraints, in both private and academic clinical settings. Parents of preterm babies need information just before and after discharge on their babies' needs and follow-up at the outpatient clinics (GarcíaReymundo et al., 2019). They (GarcíaReymundo et al., 2019) recommended that before all late preterm infants (LPIs) are released home, a follow-up work plan should be put in place considering the availability of resources. They also recommended that these LPIs should be followed for 2 years of corrected age and then twice every year to age 6. A post-discharge program following advanced NCU care for extremely preterm babies and their parents was so much applauded by Baraldi et al. (2020) because it addressed the psychological needs of the parents towards their babies' development.

It is important to note that mothers play a key role in caring of preterm babies and the education provided to them should be individualized depending on their needs which include their psychological and physical well-being (Garti et al., 2021). The first 6 months of premature babies' lives are important since they entirely depend on their mothers' breast milk alone for nutritional supply, which in turn affects their neurodevelopment among other benefits (GarcíaReymundo et al., 2019). Also, Baldoni et al., (2021) showed that the presence and participation of fathers in the care of the preterm baby in the NCU and also at home does promote bonding of the father and the preterm baby and also stabilize the mother and the family members psychologically.

2.2 Conceptual Framework

This study adopted the conceptual framework used by Lakshmanan et. al. (2017) that was derived from the Kenner transition theoretical framework as seen in Figure 1. The model has five categories of parents' challenges and concerns namely: provision of information by the health care provider, parents' preparedness, support system, transition to outpatient care, and psychosocial support. Information provided by the healthcare givers to the parents of preterm babies about their babies' condition and the expected date of discharge builds their confidence and improves their interactions with the preterm babies not only when they are in the hospital but also at home. It is necessary to note that the preparedness of the parents for transitioning into full parenthood and home care depends on the information provided while in NCU with their babies. Once there is a lack of appropriate information for this transition, parents feel inadequate and not prepared to take up the task of caring for her/his child solely at home without the help of a health professional. This will in turn affect the parents' confidence and parent-child interactions negatively both in NCU and at home post-discharge. For continuity of care, parents of preterm babies need to be followed up by a primary caregiver not limited to a paediatrician in the out-patient clinics. This can be done through phone calls, video chats, webcams and/or physical visitations. Due to complications related to prematurity, primary caregivers and paediatricians through follow-up clinics will be able to manage them while at the same time enhancing parents' confidence and parent-child interactions during visitations and even through mobile phone interactions.

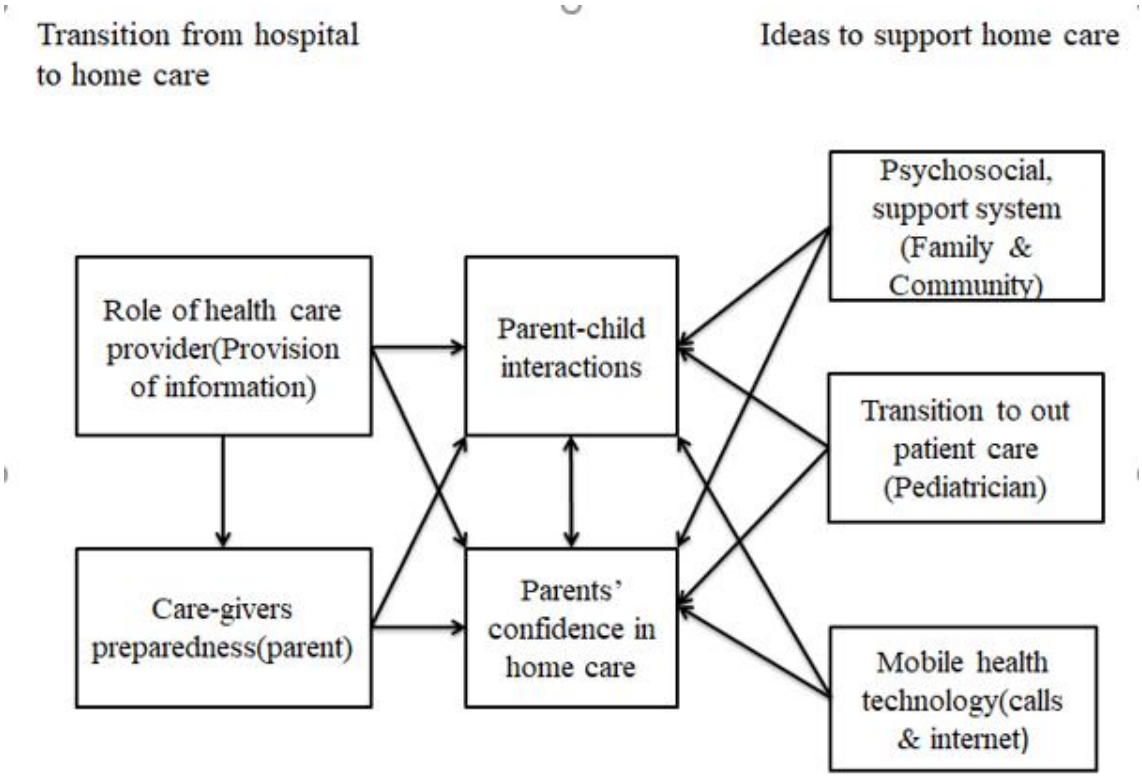
At the community level, parents of preterm babies need a good support system which will help them raise their babies in a healthy environment. Other family members, peer group members, leadership of the community, and religious leaders have a role as a support system to provide both financial and psychosocial support for parents of preterm

babies. The community should be encouraged not to stigmatize parents of preterm babies because stigma will hurt the parents' interactions with their children and confidence in taking care of their babies. The family members, peer group members, and leaders are either male or female and they are Christians or non-Christians.

The constructs adopted in this study are the provision of information, Preparedness of caregivers, support system, mobile health technology and transition to out-patient clinics.

Figure 1

Conceptualization Framework



Source: Lakshmanan et. al. (2017)

The conceptual framework above covers the whole process of transitioning right from inpatient care (NCU), coping at home, and outpatient follow-up clinics for the preterm child and the parent. Parent-child interactions and parents' confidence in care can be affected by any of the five categories named above. At the same time, parent-child interactions can be affected by the confidence of the parents and vice versa.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

In this chapter, research design, study location, population, recruitment, sampling procedure, sample size, inclusion and exclusion criteria, data collection tools and procedures, analysis and management of the data collected, and lastly ethical considerations are included.

3.2 Research Design

The study adopted the phenomenological research design. This research design used by the researcher sought to understand the lived experiences of individuals. Further, this design was used to explore the experiences of caregivers of preterm babies after they were discharged from the newborn care unit (Creswell, & Poth. 2019).

3.3 Location of the Study

The study was conducted in Kericho County. A.I.C Litein Mission and Kapkatet Sub County hospitals were chosen for this study because of their proximity to one another and the high volume of preterm babies that they delivered, cared for, and did follow up with.This provided an excellent population for study. Each hospital admitted an average of 15 premature babies every month totalling 900; for the past 5 years (2017-2022) in each hospital. About ninety per cent of these preterm babies got discharged home alive from A.I.C Litein Mission Hospital; but, there was no clear records of the percentage babies born on preterm basis that came back for a follow-up and those lost for follow-up. In Kapkatet Sub-County Hospital, eighty-five per cent of the preterm babies were discharged home healthy, while fifteen per cent succumbed to death due to complications directly related to prematurity. There were no other rural locations in the country where

two hospitals providing roughly the same level of neonatal intensive care for premature babies were this close together.

There were no reliable statistics on what number came back for follow-up in either of the hospitals. In these two hospitals, there was no home visit program to follow-up preterm babies or their parents post-discharge. This study was the first to be undertaken in the county and will be used to give recommendations on follow-up for caregivers of preterm babies to the community.

3.4 Population of the Study

The principle investigator targeted about a hundred and twenty parents and other caregivers of preterm babies who attended the outpatient clinics for follow-up in Kapkatet County Hospital and A.I.C Litein Mission Hospital and were discharged between August 2021 and February 2022. The hundred and twenty caregivers are derived from the attendance records of the paediatric outpatient clinics and discharge records from NCU of the two hospitals that were present at the time of the study.

3.5 Sampling

3.5.1 Sampling Procedure

Homogeneous purposive sampling which is a non-probability procedure was used to select the participants from Kapkatet County and A.I.C Litein Mission Hospitals outpatient clinics in Kericho County. The caregivers of preterm babies were singled out from those attending the paediatric outpatient clinics and each one of them had an equal chance of participation.

3.5.2 Sample Size

The sample size was arrived at once saturation had been reached, that is, once the information being given became repetitive of what had already been said. It was anticipated that saturation would be achieved after interviewing about 20-30 participants but it was reached after interviewing 10 participants(Moser & Korstjens, 2018). However, six more caregivers were interviewed to be sure that no information was missed.

3.6 Recruitment

On paediatric outpatient clinic days, the researcher identified caregivers of preterm babies on follow-up and informed them about the study how it will be conducted, where it will be conducted, who was eligible to participate, and who the researcher was. These caregivers were invited to participate willingly on scheduled dates and times. All parents and other caregivers whose babies were born before 37 completed weeks of gestation and were discharged home at least six months ago were recruited and their contact details were taken for communication purposes. Once the approval had been given for data collection, the participants were contacted through phone calls and face-to-face during clinic days and given specific dates and times for the interview by the principal researcher.

3.7 Inclusion and Exclusion Criteria

All caregivers of preterm babies discharged home with their babies between August 2022 and February 2023 were recruited for the study. Caregivers who could prefer interviews to be conducted in the comfort of their homes were residing within Kericho County and specifically not more than 10km from the two research centres were also included.

All caregivers from other counties who would have liked the interviews to be conducted at their homes were excluded. Caregivers of preterm babies with gross congenital anomalies were also excluded due to the special care and needs of these babies.

3.8 Data Collection Instruments

In-depth interviews were used to collect data and an audio recorder was used to capture the interviews. The study adopted part of the questionnaire used by Garti et al. (2021), see Appendix I and Appendix III. The questionnaire was piloted in a nearby facility before it was administered to the participants.

3.9 Data Collection Procedures

The participants were oriented to the objectives and the purpose of the study on the material date. The above information aided the participant to voluntarily decide to participate or decline. It was clearly explained that there would be no victimization if one declined to participate. The participants were also informed that the information given would be confidential and private since it would be only accessible to the researcher. They were allowed to ask any questions they had and clarification was given as it necessitated. Verbal and written consents were obtained from the participant by appending his/her signature after they were satisfied with the information given. Only then did the researcher administer the interviews while capturing the data with an audio recorder. 75% of the in-depth interviews were conducted at the outpatient clinics in Litein Mission and Kapkatet Sub-county hospitals while 25% were conducted at the participants' homes. The selected places of interviews were quiet, comfortable, and only accessible by the researcher and the participant to ensure privacy and confidentiality. There were no benefits for anyone who accepted to participate. 3 participants exhibited signs of psychological disturbance and were referred for psychological counselling by a

qualified psychologist who had been identified and informed before the interviews. The interviews lasted between 20-45 minutes. Participants were allowed to respond in the language they were more comfortable with but ultimately this was translated to English.

During the interviews, an audio recorder was used to record the proceedings of the interviews for data analysis later. Transport was reimbursed in hard cash by the principal researcher at the end of each interview for those who specifically came for the interviews while those who were interviewed in the comfort of their homes received ksh500 as an appreciation of their time. The audio-recorded data was transcribed into written hard copies; narratives were identified after careful reading and listening through. The narratives were coded, sub-themes picked and eventually organized into themes after careful interpretation of all data collected. To ensure the completeness and integrity of the data during data collection, the researcher used the household interview (HHI) and key informant methods of triangulation. The voice recorder and all data collected were put under lock and key only accessible by the researcher. The voices were distorted and all identifiers were removed by the researcher for confidentiality purposes. All the data will be kept for five years after which it will be discarded by shredding the papers and deleting the audio recordings.

3.10 Data Analysis and Presentation

The researcher analysed collected data using thematic analysis as suggested by Kiger and Varpio (2020). Themes were identified and documented from the collected data following the steps illustrated by Kiger and Varpio (2020).

Step 1: Familiarization with Collected Data – This Involves transcribing the entire data and reading in between the lines to understand the intended message or idea.

Step 2: Generation of Initial Codes – After familiarization with the data, specific and outstanding ideas are identified and coded accordingly, collating each code with the relevant data in preparation for step 3.

Step 3: Search for Themes– Coded data is analysed, combined, and compared to each other to form meaningful themes of the collated data.

Step 4: Reviewing of themes – Each potential theme is reviewed to ascertain whether the relevant codes and the extracted data have enough supporting and coherent data for each theme. All themes should be harmonious with the entire data set creating a thematic map.

Step 5: Definition and Naming of themes – The specifics of each theme are further refined from the thematic map creating clear definitions and specific descriptions of each theme.

Step 6: Production of Report/manuscript – A final report is written after analysing and describing the findings by using both narrative descriptions and representative data extracts.

3.11 Ethical Considerations

Permission from the Institute of Postgraduate Studies (IPGS) of Kabarak University was sought after the successful defence of the proposal to seek ethical approval from Kabarak University Research Ethics Committee (KUREC) for the study. Once the KUREC approval was issued, a research permit from the National Commission for Science, Technology and Innovation (NACOSTI) was sought and finally, ethics approval from the Kapkatet sub-County Hospital ethics board was also sought before data collection would commence. A letter from A.I.C Litein Mission Hospital was issued giving a go-

ahead to collect data. The participants were fully informed of the aim and objectives of the study after which the researcher proceeded to obtain an informed verbal and written consent from them. The researcher anticipated psychological disturbance during interviews. Three (3) participants were psychologically disturbed and benefited from the free psychological counselling services that were put in place specifically for these eventualities. No one opted out of the study during the interviews since they were free to do so with no consequences.

The participants' confidentiality was assured since the interviews were conducted at the client's place of convenience which was only accessible to the client and the researcher. The anonymity of the collected data through in-depth interviews was maintained right from the beginning by removing all the identifiers from the data which would link the participant to a specific institution or community. During data analysis, no one could identify the participant by listening to the recorded interviews since all identifiers had been removed and the voices distorted. To prevent the collected data from dissemination, possible theft, or copying, it will be locked in a cabinet only known and accessible to the researcher. The electronic device used for recording interviews will be under lock and key, and only be accessible by using a password that is only secretive to the researcher. Coded transcripts will be kept separately in a confidential place for a period of 5 years. The findings will only be shared by the researcher with the relevant institutions and shall only be used to improve service delivery at the community level as they integrate it with hospital services.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSION

4.1 Introduction

This chapter presents and discusses the findings and interpretations of the data collected in line with the objectives.

4.2 Background Information of Participants

The study sought to establish the demographic characteristics of the respondents like gender, age bracket, education level, marital status among others as described in Table 1.

Table 1

Socio-Demographic Characteristics of Caregivers

Characteristic	Total		Percentage (%)
Gender			
Male	3		18.75
Female	13		81.25
Age (Years)			
25 – 29	2		12.5
30 – 34	2		12.5
35 – 39	11		68.75
40 – 44	1		6.25
Education Level			
Secondary	5		31.25
College	11		68.75
Marital Status			
Married	14		87.5
Single	2		12.5
Employment Status			
Unemployed	12		75
Employed	4		25
No. of Children			
1 – 2	4		25
3 – 4	12		75
Gestational age at birth	Weeks	N	
Extremely preterm	< 28	4	25
Very preterm	28 – 32	8	50
Moderate to late preterm	32 – 37	4	25
Birth weight ranges	Weight (grams)		
Extremely low birth weight	< 1000	1	6.25
Very low birth weight	> 1000 to 1499	3	18.75
Low birth weight	1500 to 2500	12	75
Hospital Stay (Days)			
1 – 30	14		87.5
31 – 60	1		6.25
61 – 90	1		6.25

A total of twenty (20) caregivers were contacted through phone calls, out of which, three(3) declined to participate in the study due to personal reasons, and one could not make it because she had relocated to a different county which was too far for her to travel back to Litein. Sixteen (16) participants did participate in the study after consenting both verbally and in appending their signatures. Three (18.75%) were male while thirteen (81.25%) were female. Sixteen caregivers aged 25 – 42 years were interviewed. Fourteen (87.5%) caregivers were married and lived with their spouses however; two (12.5%) of the participants were single mothers. Four (25%) had two children and twelve (75%) had at least three children exclusive of the preterm baby.

Twelve (75%) of the caregivers said that it was their first time to have had a preterm baby while four (25%) had a preterm baby prior to the one they have. Sixteen (100%) of the caregivers had a formal education but only four (25%) were employed while twelve (75%) were unemployed. Four (25%) of the participants had their preterm babies born before 28 weeks' gestation (extremely preterm), eight (50%) born between 28 weeks and 32 weeks (very preterm), and four (25%) born between 32weeks and 37 weeks (moderate to late preterm) respectively. Their preterm babies' birth weight ranged from 900grams to 1900grams: less than 1000 grams (extremely low birth weight) one – 6.25%, more than 1000 grams but less than 1499 grams (very low birth weight) three – 18.75%, and more than 1500 grams but less than 2500 grams (low birth weight) twelve – 75%. Their hospital stays ranged from 7 days to 90days with an average of 30 days of admission in NCU as illustrated in Table I).

4.3 Analysis of the Results

The verbatim data that was audiotape was transcribed to 50 pages of written hard copies of the data. Two research assistants independently read through the transcripts and

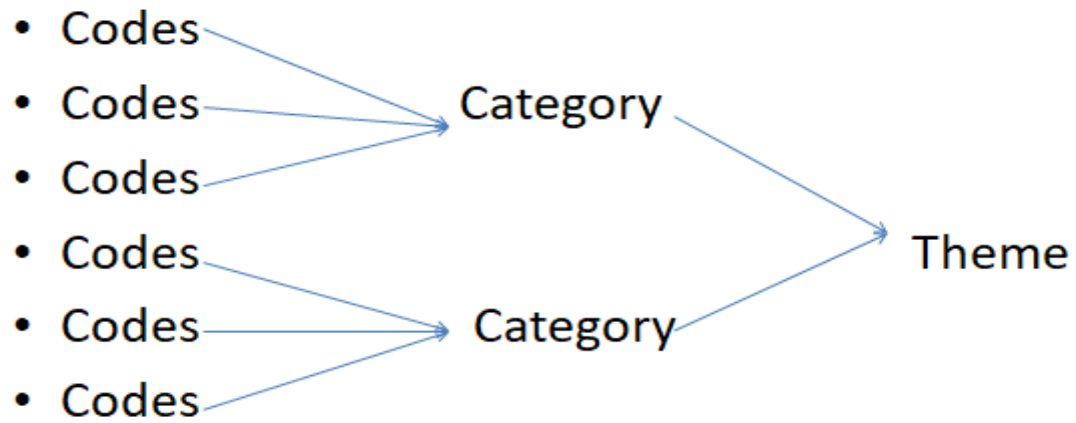
analysed the raw data line by line. Open coding was used to come up with codes after the common phrases were grouped together and eventually organised into codes. The research assistants agreed on the commonality of the codes that was at 85% and finally the codes were put into categories from which the subthemes and themes were generated.

4.3.1 Interpretation of Coding Process Used

Figure 1 depicts the process through which similar codes are grouped together to form specific categories from which themes are generated. Each code points to a certain narrative which when given a meaning, it falls into a group that will eventually form a category. Finally, the categories will be combined giving rise to themes.

Figure 2

Showing Interpretation of the Coding used in the Analysis



The audio recorded interviews were carefully listened to, and then transcribed to written hard copies. The transcripts were read word by word, line by line and in between the lines so as to understand the message that was passed. After thorough reading and re-reading, codes were identified as listed below. These codes consist of the statements that were prominent and repeated several times during the interviews as a reassurance that saturation was achieved as shown in the codes in Appendix III.

4.3.2 Categories and their Codes

Related codes were grouped together into categories and given an overarching title as shown below. The above codes were organized into categories whereby low self-esteem and social isolation fall under stigmatization while the rest remained as categories on their own. Finally, three themes were realized from these categories as shown in Table 2.

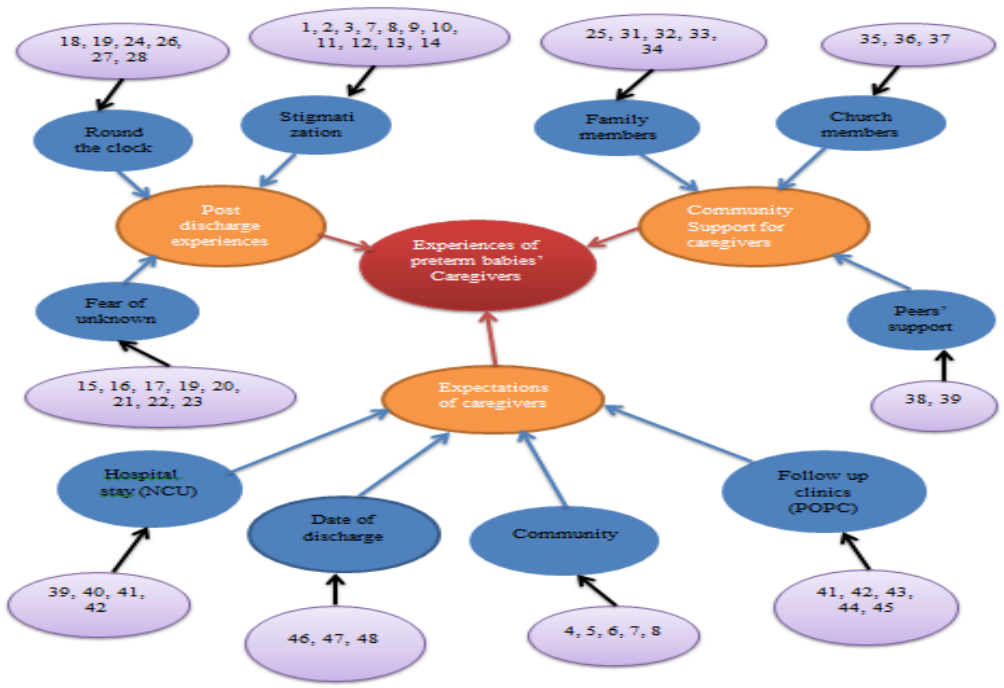
Table 2

Showing Codes, Categories and Themes

Codes	Categories	Themes
1, 2, 3, 9, 7, 8, 10, 11, 12, 13, 14	Stigmatization	Post Discharge
Experiences		
15, 16, 17, 19, 20, 21, 22, 23	Fear of unknown	of Caregivers
18, 19, 24, 26, 27, 28	Care round the clock	
39, 40, 41, 42	Hospital stay (NCU)	Expectations of
		Caregivers
46, 47, 48	Date of discharge	
4, 5, 6, 7, 8	Community	
41, 42, 43, 44, 45	Follow-up clinics (POPC)	
25, 31, 32, 33, 34	Family members support	Community Support
		for Caregivers
35, 36, 37	Church members support	
38, 39	Peers support	

Figure 3

Showing the Visualization of Codes, Categories and Themes



4.4 Experiences of Preterm Babies' Caregivers while Taking care of their Babies at Home

All caregivers had both good and bad experiences at home which ranged from fear of the unknown of the baby's eventuality, stigmatization leading to low self-esteem, social isolation and self-neglect, and overprotection of the preterm baby to great psychosocial and economic support given by their spouse, peers and even relatives within the community. The caregivers had to take the doubled role as not only parents but also as healthcare providers. They shouldered all the responsibilities with perseverance even though no one had any experience of taking care of a preterm baby at home. Uncertainty was high and any abnormal behaviour of the preterm baby could cause a lot of anxiety and needed swift actions from the caregiver. The negative experiences were expressed as follows:

4.4.1 Post Discharge Experiences

Sub-theme I: Stigmatization

All the caregivers faced stigmatization in the community and as a result, some felt inadequate leading to low self-esteem and eventually socially isolated from the community.

One mother had this to say:

> '*Waoo! What an experience to even talk about!! People see you as a failure… It is not easy, you always ask yourself, why is she so tinny? Why is she so different from others? What did I do wrong?*' **Caregiver A (Mother).**

Another caregiver said this while crying;

> *'Sometimes when I approached someone with my child, the person will leave to avoid me and my child…*(sobs). *That is so hurting and discouraging if not disappointing or inhuman. The child is innocent but an adult doesn't understand'* **Caregiver E (Mother).**

Some used very harsh words to describe premature babies as one mother put it;

> '*My friends asked me, what kind of a woman are you giving birth to a very small baby? He is too small even my shoe is big; his size is that of a rat'* ***Caregiver C (Mother).***

Another caregiver said:

> '*I didn't have that courage to carry our baby to the clinic since I feared what our neighbours would say about the size of our child. Sometimes I could hear them say; how is she going to carry that small thing called a baby! It can slip out of the blankets without her noticing…*' **Caregiver G (Mother).**

Another mother narrates;

> *'I used to lock myself inside because other women (mothers) used to say that this child is too small. You feel bad. Because my child was too small, I could not attend meetings'* **Caregiver F (mother).**

Sub - Theme II. Fear of Unknown

Every one of the participants was concerned about the safety of their preterm babies. Some feared that something bad could happen to their babies, others were afraid their babies might be injured or die, and as a result of these insecure feelings, they could not trust anyone to take care of their babies as they could do themselves. This anxiety started right on the day of discharge since majority of the caregivers were not prepared either due to lack of information or the fear of unknown for their baby outside the hospital setting.

Caregiver A, who is a mother said;

> *'I was not ready to go home because you see, I will be alone..no nurses or doctors for support.. I was scared'* **Caregiver A (Mother).**

A father who had no idea what to expect at home said;

> *'I had mixed reactions when the doctor said that we are going home'*
> **Caregiver I (Father).**

One caregiver (mother) elaborately said this:

> *'You need more time, you are forced stop every other chore because you don't know what will happen to him; you cover him well but then he covers himself including the head, he can die. Sometimes he vomits through the nose…..this scares me a lot. I wonder whether he will speak, walk or he will be disabled…'(tears),***Caregiver D (Mother).**

Another father said:

> *'I could sneak from work so as to keep checking if he is okay and sometimes carry her for 30 minutes before i sneak back to work'***Caregiver B (Father).**

Another mother said:

> *'…while at work I constantly imagined that something wrong might happen to her!!!'***Caregiver C (Mother).**

Due to the feelings of insecurity of her baby, one mother resigned from her job in order to protect her preterm baby. She said:

> *'Wherever I went, I took her along with me since I could not trust anyone that could take care of her as I do… I actually quit my job in the second month so that I could take care of her and protect her from any trauma'*
> Caregiver C (Mother).

Sub-theme III: Care Round the Clock

Majority of the caregivers said that their babies needed more time to take care of them compared to term babies. They felt fatigued and exhausted because they barely had enough time to rest. Sometimes some could fall asleep while seated. They were unable to attend to other chores because of the preterm baby's demands.

One mother said:

> *'This child probably needed 15 to 20 hours a day for proper care.. My hubby could sometimes close his business so as to take care of us'* Caregiver A (Mother).
>
> '*…My mother took leave to take care of me and my son '***Caregiver G (Mother).**

Another caregiver (mother) added:

> *'Feeding as required was a challenge leave alone waking at night every 2-3 hours… was an uphill task that needed sacrifice and dedication. I could feel fatigued and so tired that during the day I could fall asleep while seated. Anyhow'*(laughter) **Caregiver D (Mother).**

Mother E crowned it all when she said;

> '*Having a premature baby takes all your energy and time compared to a normal baby. The one who has been born maturely has no much work real… it's like a walk-over kind of…'* Caregiver E (Mother)

4.4.2 Community Support for Caregivers of Preterm Babies

All caregivers expressed their gratitude for the support they received from their spouses, relatives, and the community at large. Of note, all women (mothers) appreciated the psychosocial support their husbands gave them including finances, doing house chores like cleaning the house, utensils and laundry work. The mothers' in-laws and in-laws played a great role in the support of caregivers of preterm babies. These were expressed as follows:

Theme 3: Support given to Caregivers

Sub–Theme I: Family members

One mother with a smile on her face stated that;

> *'My in-laws said that they don't care about the size, she is ours, no matter what, we will take care of her even if I refuse her, and she is our blood'* Caregiver G(Mother).

Another mother applauded her mother-in-law for her support as expressed in her statement below.

> *'… My mother in-law used to cook, wash all the clothes, mob the floor and any other thing that needed to be done; she could go to school to pick our son…'***Caregiver K(Mother).**

The sisters were not left behind in support of the caregivers as one father said;

> *'My sisters took turns to do the cooking, cleaning of the house, washing the dishes, washing and dressing our preterm baby, fetching water from the river and even escorting our son to and from school every day'* **Caregiver I (Father).**

Majority of the caregivers expressed their innermost gratitude towards their spouses for the support they received from them. For example, one woman said;

> '*My husband would wake up early, do all the cleaning in the house, cook breakfast, prepare the other children for school and escort them to school. He used to make sure he has cooked my lunch and packed it well for me…***'Caregiver K (Mother).**

Another woman was proud of her hubby as she expressed it in her statement:

> *'…He was not only my husband but my counsellors and everything in this world'* **Caregiver H (Mother).**

Sub–Theme II: Church Members

The church members were a source of hope and encouragement for many through prayers and visitations. One mother said:

> *'My church members visited me, prayed for the good health of my son and protection from evil*..they stood by my side wherever I needed them' Caregiver J (Mother).

Another mother satisfactorily said:

> *'..... they* (church members) *were my pillar when my faith was weak'* Caregiver H (Mother).

Sub–Theme III: Peers' Support

Over 75% (13) of the caregivers said that they were so much encouraged by other mothers who had preterm babies within their locality. They were visited and even shown healthy and energetic teenagers who were born prematurely. One mother shared her encouragement by saying;

> '*She told me not to fear, her child was even smaller than mine but now he is a grown man like any other man….* He will be a man. '*This encouraged me'* Caregiver H (Mother).

4.4.3 Expectations of Caregivers with Preterm Babies

Every caregiver expressed the need for experienced staff members to work in NCU so that they would give the required services. Some said that because of the inexperienced nurses, communication was impaired. On the other hand, the majority of the caregivers were concerned about the sympathy of the nurses and how rude they were to them as expressed below.

Theme 4: Expectations of Caregivers

Every living being has expectations in every situation that is encountered in life. It was not different with the caregivers who participated in this study. They did express different expectations during their hospital stay, on the day of discharge, at the community level and lastly during their follow-up clinics. The caregivers had unmet expectations right from the time they were in the NCU, on the day of discharge, back at the community and when attending the paediatric outpatient clinic as illustrated below.

Sub-Theme I: Expectations during hospital stay (NCU)

One registered her disappointment while in the Neonatal Care Unit by saying;

> *'I expected the staff working in NCU to be understanding….. as in to explain the procedures, why they are doing it, teach us what to do especially when it comes to feeding but unfortunately it was tough'* **Caregiver A (Mother).**

Another caregiver said that she expected to be given clear directions on how to express milk for her preterm baby but it was not done as she put it:

> *'I was harassed the first time with nurses…she said to me, 'go and express your milk'... I didn't know how to do it and I expected to be directed or at least be shown how to do it since I have never done it before'* **Caregiver D (Mother).**

Another caregiver said as she was crying;

> '(*Crying..*)*In hospital, when you are in nursery you have no idea how to feed your child…* you are told *'mum feed your child, it is your effort that will make you leave the hospital..it is a must you know how to feed your child'…….they talk arrogantly'* **Caregiver K (Mother).**

One mother with tears rolling down her cheeks said;

> *'I used to laugh a lot but my laughter was not real laugher but pain and fear…. I needed someone who couldn't judge me on my child but to understand me to at least give me hope (Sobs)*' **Caregiver L (Mother).**

On the day of discharge, one mother lamented that she was not prepared to go home and here is what she said;

> *'... I was not ready to go home, not prepared.*' **Caregiver N (Mother)**

Despite the disappointments registered above, there were appreciations too from the caregivers for what the hospitals had done for them. A mother said;

> '*This hospital did everything they could to have my baby alive, am thankful although they have their dark side'* **Caregiver J (Mother)**

Sub–Theme II: Expectations on the day of discharge

At some point, every caregiver of the preterm baby had hopes of going home unfortunately; more than eighty per cent recorded their disappointment that they were not prepared on the day of discharge. A father said;

> *'I had mixed feelings when were told that were have been discharged home'* **Caregiver B (Father)**

In conquering with other caregivers, a mother said;

> *'I was not ready to go home, I wish they could have prepared me in advance'* **Caregiver O(Mother)**

Sub–Theme III: Expectations during follow-up clinics (POPC)

When coming for the follow up clinic, all the caregivers looked forward for an understanding and sympathetic staff who would give them hope and encouragement; instead of shouting at them and answering them rudely. They said that doctors were friendlier than nurses and preferred talking to the doctor alone.

One caregiver, being heartbroken had this to say;

> *'I come from home stressed expecting to get someone who would talk to me nicely but guess what! While cueing, the nurse rudely talks to you as if you do not have a problem; you only like coming to hospital…it is heart-breaking '***Caregiver C (Mother)**

Another mother with a sigh and shrugging her shoulders said;

> *'…who am I to insist on what the doctor is not seeing!!'***Caregiver H (Mother)**

One mother insisted several times by saying;

> *'Take hid of what the mother says, when I say the child has this, the doctor should listen instead of brushing it off '* ***Caregiver*** **E (Mother)**

Sub–Theme IV: Expectations from the community

The caregivers of preterm babies registered their disappointment as they were taking care of their babies in the community. They could not understand why most community

members discriminated against them and their preterm babies instead of being supportive to them.

The statement made by one caregiver as she was crying said it all.

> *'Sometimes when I approached someone with my child, the person will leave to avoid me and my child(sobs) that is so hurting and discouraging if not disappointing or inhuman. The child is innocent but an adult doesn't understand it'* ***Caregiver*** **E (Mother).**

A mother of two children said;

> *Why are people like this? As in… why do they think we are not women as they are? Instead of encouraging us, they condemn us***.. *Caregiver G* (Mother)**

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter discusses the themes generated in detail, makes a conclusion and gives recommendations based on the findings.

5.2 Summary of the Findings

This study aimed at describing the experiences caregivers of preterm babies had at home in the first 6 months' post-discharge from the neonatal care units in A.I.C Litein Mission Hospital and Kapkatet Sub-County Hospital. The following themes are well discussed as generated.

5.2.1 Post Discharge Experiences

Pregnancy for most women is a happy moment for them and they look forward to delivering a healthy baby at term however, this is not always the case. Some babies are born before their expected time of delivery and these are categorized into extremely preterm, (< 28 weeks), very preterm (28 to 32 weeks), and moderate to late preterm (32 to 37 weeks) babies. In this study, the caregivers stated that they did not expect to have a preterm baby and due to that, they faced a range of challenges in taking care of their preterm babies in the first months after discharge in agreement with Lasiuk et al., (2013). In this study, Lasiuk and colleagues stated that the main issues were rather related to the prolonged uncertainty than the gestational age of the preterm baby. This was in contrast to the mothers in this study whose greatest concern at first was the gestational age and the size of the baby. This translated to the way they were perceived in the community. Some caregivers lamented that their babies were called names that were heart-breaking because of their sizes. Those names included as small as a rat, smaller than a shoe.

Several mothers in this study did not know what to expect or do once they left the hospital in terms of their role in taking care of the preterm baby as confirmed by Lasiuk et al., (2013). Once the caregivers were discharged home, they said that it was difficult, and it needed a lot of time to take care of a premature baby compared to a baby born at term.

Time was a major factor in caring for the preterm baby at home. The majority of the mothers in this study needed at least 15 hours to care for the babies' daily needs making it difficult to attend to other chores like doing business as identified by Gondwe et al., (2014); and Amorim et al., (2018). Some babies especially those born with extremely low birth weight needed round-the-clock care affirming the findings of Amorim et al., (2018) who stated that care of the very preterm baby needed 24 hours. This was echoed by Gondwe et al., (2014) who highlighted the time burden needed to take care of a preterm baby leading to negligence of other duties like farming, business, and even cleaning the house. The study of Amorim et al., (2018) also observed that the caregivers of extremely preterm babies were negatively impacted in terms of their quality of life because they had no time to attend to other calling duties which could include time to rest.

Due to lack of enough sleep, Henderson et al., (2016) observed that the caregivers felt fatigued, tired, and sometimes disoriented during the day and these would lead to negative feelings like anger and resentment towards their preterm babies. These negative feelings were worse among the employed caregivers and their performance at work was also affected. As a result, some caregivers decided to resign from their employment to have enough time with their preterm babies at home while other caregivers stated that they used to sneak from the office so that they could check on the well-being of their babies. It is important to note that resigning could not have been an option for the

mothers if this was in developed countries like Finland and Germany where maternity leave extends for more than six months (Moring, A., & Lammi-Taskula, J. 2021) unlike in Kenya where it is only ninety days according to the laws of Kenya, Employment Act 226. At the same time, sneaking from work to check on the baby could have been avoided if at workplaces there was space provided for breastfeeding mothers as it is done in some of the developed countries.

Once at home, many of the caregivers in this study like those of Nabiwemba et al., (2014) said that their needs ranged from 2 hourly feeding, keeping the environment clean and safe, and keeping the baby warm. The study of Nabiwemba et al., (2014) was conducted in the neighbouring country of Uganda which has almost the same psychosocial economic and healthcare system challenges as Kenya. The mothers in the Nabiwemba et al., (2014) study were categorized into those who delivered at home and those who delivered in a hospital. This was not the case in this study which had only mothers whose preterm babies were delivered in the hospital pointing out the need for this study to have included caregivers whose preterm babies were born at home. The two categories were compared by Nabiwemba et al., (2014) in terms of cord care and keeping the baby clean. They discovered that mothers who had hospital delivery were better placed in terms of knowledge of cord care and keeping the baby clean however, exclusive breastfeeding became a challenge for both groups while at home.

Apart from the round-the-clock needs described above, fear of the unknown was a major topic in the discussions with the caregivers. Many of the caregivers indicated that they were not ready to go home because of the uncertainties their preterm babies could face at home in the absence of a nurse or doctor for their help or support. The majority of the caregivers expressed their anxiety whether they were at home or away. This was in agreement with Fowler et al., (2019) who pointed out the emotional stress parents of

preterm babies undergo while in NCU and after discharge. A mother expressed her fears when she said that she was scared and at the same time worried whether her baby would ever speak or walk. Another caregiver (mother) carried her preterm baby wherever she went because she feared for her safety. The caregivers in this study constantly feared that something wrong could happen to their babies while they were at work causing them to be psychologically and emotionally disturbed. These same findings were also illustrated in Henderson et al., (2016); Carson et al., (2015) studies. No wonder some caregivers resigned from work and others could sneak from work because they feared for the safety of their preterm babies. Due to the fear of the unknown, the caregivers did take all the measures they thought could guarantee their babies' safety and good health.

These safety measures included covering the preterm baby with more than one blanket to prevent the baby from getting pneumonia; and taking turns to check on the baby during the night since the baby may cover her face and suffocate or vomit through the nose and could be chocked by the vomitus and lastly, other caregivers could not allow the other siblings to take care of the preterm baby because they thought that they could hurt the preterm baby. For example, caregiver C (Mother) could not let her children take care of the preterm baby girl because she thought they could hurt her. Another mother used to cover her preterm baby girl with two or more blankets to keep her warm and prevent her from getting pneumonia. These fears led to psychological trauma for the caregivers and as a result, some caregivers were so affected to the extent that they could not produce enough milk for their babies. The emotional and psychological stress of parents of preterm babies was summed up in a study conducted by Carson et al., (2015) in the United Kingdom which pointed out that the risk of developing postpartum depression among mothers and depression among fathers of preterm babies was doubled compared to that of mothers and fathers of term babies.

The contributing factor for the fathers of preterm babies to developing depression twice as much of those with term babies, according to Premji et al., (2019), was that the father's role in the care of a preterm baby was overlooked not only in the NCU but also at home. At the same time, Jerntorp et al., (2021) in their study also found that fathers felt isolated from their spouses and their preterm babies while in the hospital and even at home affecting them emotionally. However, in this study, fathers were less affected emotionally compared to mothers and they became counsellors in their families in line with the findings of Baldoni et al., (2021) study which ascertained that the father's presence and participation in the care of a preterm baby had a positive impact on the stability of the mother's physical, emotional, and psychological well-being. This support from the men (fathers) was important since most caregivers especially mothers were treated as failures in the community because they had given birth before their expected date of delivery. This discrimination was connected by the Koenraads et al.(2017) study to a lack of sensitization and inadequate knowledge among community members on premature babies and their caregivers. Some community members called the preterm babies names that were so heartbreaking to the majority of the caregivers.

One caregiver, a mother, exclaimed with tears rolling down her cheeks that her friends asked what kind of a woman she was giving birth to a very small baby before the time of delivery. Some friends compared the size of the preterm babies to the size of their shoes while others compared them to the size of a rat. "His size is too small even my shoe is big and/or his size is that of a rat," they said. This brought out the Kalenjin belief which assumes that a real woman should always give birth to a child at term and anything falling short of that is regarded as abnormal and the woman is looked down upon. At the same time, the society in which this study was conducted also does believe that the woman (mother) of the preterm baby must have committed an offence or contributed in

one way or another for her to have given birth before the stipulated time of delivery. As a result, these caregivers specifically mothers felt discriminated against and socially isolated as identified in the Gondwe et al. (2014) study making them have low self-esteem unlike the fathers who society esteemed to be blameless in this matter. Caregiver D bitterly lamented that no one came for a cup of tea in their house as it is a custom in the community to celebrate a newborn. This did happen because the baby was too small. Another caregiver was so hurt after she was told not to expect anyone to come to her house since her baby was not worth seeing. She felt socially isolated, psychologically disturbed, and emotionally drained. All these amounted to stigmatization which was discussed in the study of Gondwe et al., (2014).

As a result of stigmatization in the community, women (mothers) spent most of the time indoors to avoid hearing what other women would say about them and their babies. On the other hand, caregivers more so mothers of preterm babies, unlike fathers of preterm babies, were unable to attend social meetings because the babies were too small and they feared for the safety of their babies. One mother said that she was unable to attend meetings because the baby was too small. Mother E, a single mum, used to lock herself in the house throughout the day to avoid hearing what other people were saying about her and the baby. The insults and stigma made the caregivers especially mothers feel inadequate and socially detached from the rest of the society. However, fathers were not so much affected socially since they could attend most of the social gatherings as men and also as representatives of their families. In addition to the social constraints discussed above, in some families where the in-laws and other relatives were not available to help, the men (fathers) were forced to do the house chores like laundry, cooking, and washing of the dishes. Although these men were regarded as modern men since the role of an African man was to go out there and bring food for the family as the

house chores were taken care of by the woman in the home, this strained the families' finances since men were not working as expected and their wives could not support as they were taking care of the preterm baby. For the single mothers, life was harder for them since they could not work or do any business to cater for their children and as a result, they depended on well-wishers for help as expressed by Mother E saying that she had no job, no one to support her and her child but well-wishers who were touched after she was evicted from the house since she could not pay her rent. Every one of the above challenges was vividly expressed throughout the interviews by the caregivers and in the process three caregivers (mothers) required psychological counselling which was offered in Litein Tumaini clinic after they exhibited features of depression as they recalled their worst experiences in the hospital and the community. Despite these post-discharge challenges that ranged from round-the-clock care for the preterm baby, and fear of the unknown to that stigmatization in the community, the caregivers also had positive experiences as discussed below.

5.2.2 Support Given to Caregivers

As discussed earlier, the caregivers had a wide range of bad experiences when they were in hospital and in the community but on the other hand, some had good experiences. These positive experiences constituted the physical, psychological, and even emotional support they received from their relatives, spouses, peers, and even church members. For example, Fowler et al., (2019) pointed out the need to support mothers of extremely preterm babies mentally and socially for their psychosocial stability and this could in return have a positive impact in the care of the preterm baby. This care or support starts right in the NCU and extends all the way to the community. As Fowler et al., (2019) highlighted in their study, there was great need for the nursing team to give their best psychosocial support to caregivers of preterm babies while in NCU and even after

discharge through phone calls. The benefit of phone calls was confirmed in Ericson et al., (2017) study which observed that mothers who had continuity of care through phone calls after discharge were satisfied in breastfeeding their preterm babies. Unfortunately, this continuity of care was lacking in this study due to financial constraints and lack of follow- up protocols in the two institutions as expressed by Bockli et al. (2014); GarcíaReymundo et al. 2019). Of note is that, once the caregivers were out of the hospital with their preterm babies, the family members shouldered the responsibility of giving the required support as vividly expressed by majority of the caregivers. The caregivers expressed the need for well outlined follow up procedures before leaving the hospital and the continuity of care to be extended to the community level.

To begin with, almost all caregivers said that they received much help from their relatives, especially their in-laws. In the African culture more so where this research was conducted, it is believed that once a woman has given birth, it is the responsibility of the relatives to take care of the mother and her baby for a given period of time before she would resume her daily chores. In their study conducted in Ghana, Adama et al., (2021) demonstrated that the elderly are accorded the major cultural role of ensuring that mothers of preterm babies are well taken care of. Their support included financial support, provision of herbal medication for the prevention of certain illnesses, bringing and preparation of food, and helping with house chores like laundry (Adama et al., 2021). This was demonstrated in the interviews by the majority of the participants in this study. For example, caregiver K (mother) said that her mother-in-law used to cook, wash all the clothes, and mop the floor after which she could proceed to school to pick up her grandson. The mother-in-laws in this study were expected by the community to cook and do the laundry wherever possible. They could prepare other children for school, escort them to school and pick them up in the evening from school. Another mother was so

proud of her mother-in-law because she took her annual leave so that she could take care of her and her preterm baby. On the other hand, sisters' in-law played a big role in supporting the caregivers of preterm babies by cooking, mopping the floor, dropping and picking up other children from school, and lastly, they could baby-seat the preterm baby as the mother took a nap. On the other hand, with all the help above, caregivers could have humble time for bonding with their preterm babies and this helped them to feel loved and cared for. At the same time, they were at peace mentally, psychologically, and even physically same as the parents in the studies of Jerntorp et al. (2021); and Baldoni et al. (2021). This stability and peace eventually could overt the negative feelings like hatred the parents more so mothers, could harbour towards their preterm babies as identified in the study of Henderson et al. (2016).

Apart from the in-laws, peers whose babies were born prematurely but now are grown-ups, encouraged the caregivers especially first-time mothers by teaching them how to handle their little ones to avoid at all costs, any trauma be it physical or psychological. The peers also taught them how to feed and keep their preterm babies warm as needs identified in the study of Nabiwemba et al. (2014). They also told them to mind their own business and not to listen to what other people could say that was negative about them or their children. The mothers shared their gratitude for the psychosocial support they received from those who had preterm babies within their locality. One participant (mother) cheerfully narrated that her peer's child was too small for hers but now he is a young and energetic man, so even her baby boy will be a grown man soon. This encouraged her so much and made her have a positive attitude towards her son. In addition to the peers' support received, the caregivers of the preterm babies who were married expressed their gratitude towards their partners. Men (fathers) were applauded for the financial, psychological, and physical support they provided to their spouses

(wives) as needs identified in a study done by Adama et al., (2021) unlike the findings of Gondwe et al., (2014) where men were accused of extramarital sex. Most of the women in this study gladly expressed their happiness because their men (husbands) could cook, do the laundry, take children to school and pick them in the evening and some could accompany their wives for follow-up clinics. For instance, Caregiver K (Mother) with a smile on her face narrated that her husband could wake up early, do all the cleaning in the house, cook breakfast, prepare the other children for school and escort them to school. He used to make sure he had cooked her lunch and packed it well for her. Another caregiver (mother) testified that the husband would not only accompany her to the hospital during her clinic visits for the preterm baby but he would also carry the baby himself. His presence meant emotional stability and physical support in agreement with the studies of Baldoni et al., (2021); and Jerntorp et al., (2021) which brought out the important role of a father in the care of a preterm baby. This was a unique finding in this study because it is perceived that in the African contest, it is the work of women to look after the children, cook, take them to school, and attend clinic follow-ups.

Lastly, despite all the support described above, at some point in the lives of the caregivers, they felt like their faith in keeping with the uncertainties was getting weak and they needed some supernatural power to give them hope amidst the uncertainties of life. At this point, the church came into play and became a source of hope for the hopeless. Some caregivers were visited by their church members and had them pray for their loss of faith and the preterm baby. This was important for their psychological stability in agreement with Lydon et al., (2018) who brought out the role of religious leaders together with health caregivers in supporting the caregivers of preterm babies in the community both socially and emotionally. For example, Caregiver J (mother) was grateful for the visitation of her church members, the prayers offered for the good health

of her son and protection from the powers of darkness. Mother H also added that when her faith was getting weaker, the church was the only pillar she could lean on. In every one of these supportive systems in the community like the peers' support, and support from in-laws and spouses, the church became a unifying factor for them all by rejuvenating the caregivers' hope as they were taking care of their preterm babies at home.

5.2.3 Expectations of Caregivers

The expectations of participants in A.I.C Litein mission hospital as well as those of Kapkatet sub-County Hospital did not differ and they included; having experienced staff members working in the NCU, getting the necessary information concerning the progress of their babies, being involved in the management of their preterm babies, and getting emotional, psychological, and financial support while in hospital and after discharge. The caregivers of preterm babies are expected to have experienced health caregivers who could involve them in the care of their preterm babies while in NCU till the day of discharge. At the same time, the caregivers of preterm babies looked forward to kind, sympathetic, and understanding staff members in NCU since they were not experienced in taking care of their babies. On the other hand, the preterm babies' caregivers were not ready to go home on the day of discharge since they were not prepared as they had expected. The above findings were not different from those in the studies of Fleming et al., (2016); and Wigert et al., (2014). For instance, in a study conducted in the UK by Fleming et al., (2016), parents expected to be well prepared in advance before the day of discharge. The caregivers in this study wanted to be told the expected date of their discharge and at the same time, to have a well laid follow-up program stipulating how long their babies will be followed up at the paediatric outpatient clinics.

First and foremost, while in hospital, the caregivers of preterm babies expected that the working staff in the NCU be experienced in handling them and their premature babies. One caregiver (mother) said as a matter of concern that her preterm baby had vomited through the nostril and the nurse who was on duty then was willing to help but she did not know what to do because it was her first time working in the NCU as a result the baby aspirated. Being first-time mothers of preterm babies, the caregivers also had no experience and they wanted to be given clear instructions on how to express their breast milk, how to feed their preterm babies, and how to handle the babies without hurting them. The majority of the caregivers felt that there was inadequate relaying of information about the procedures that were being conducted on their babies, the progress of their babies, and what to expect as discussed by Wigert et al. (2014) study. In this study, Wigert et al. (2014) realized that with inadequate communication in NCU, parents of preterm babies felt neglected, lonely and overwhelmed with responsibilities. To overcome these challenges, Garti et al. (2021) suggested that dissemination of information should be individualized to meet the expectations and needs of every caregiver of the preterm baby not only while in NCU but also at home. Caregiver A (mother) clearly stated that she needed someone who was not only understanding but also one who could precisely explain every procedure to be performed on her child and why that procedure was important.

For instance, when blood samples were being taken for investigations or when inserting a nasogastric tube for feeding of the baby, the caregivers felt uncomfortable since little information was given as to why the procedures were necessary. Clear communication from the healthcare providers on any procedure was very much essential for the psychological and emotional stability of mothers and these findings were the same as those of Fowler et al., (2019) study. Mothers were concerned about the sympathy and

empathy of the staff members working in the NCU towards them and their premature babies. They wanted an understanding and kind staff member and a friendly environment since they were already psychologically traumatized, socially isolated, physically fatigued and emotionally disturbed (Wigert et al., 2014). A mother lamented that some health caregivers used to talk to them arrogantly instead of being polite and kind to them. Mother L said as tears rolled down her cheeks that she used to laugh a lot but her laughter was that of pain and fear. She needed someone who could offer her some hope instead of being judgmental to her and her baby.

Caregiver D being a first-time mother and more so of a preterm baby, felt harassed when she was asked to go and express her breast milk for the baby. She said that she had no idea what to do and she expected the nurses to have at least taught her to do it. Another mother broke into tears when she recalled how she was humiliated in NCU since she could not express milk as ordered by the nurse on duty. Meanwhile, the fathers who were interviewed wondered what their role was in the care of their preterm babies in NCU. These fathers said that they had no time to bond with their babies and even their spouses, unlike the fathers in the Jerntorp et al. (2021) study who were involved in the care of their preterm babies while in NCU and had time to bond with their preterm babies. This could have been as a result of the locality's belief that the work of caring for a child in a hospital is a mother's duty and at the same time, the working staff members were not informed of the father's role as highlighted by Mörelius et al., (2021); Jerntorp et al., (2021).

On the day of discharge, over 75% of the caregivers said that they were emotionally and psychologically not prepared to transition from hospital care to home care because of inadequate sharing of the required information as outlined in the findings of Fleming et al., (2016).In this study, Fleming et al., (2016) suggested the use of locally generated

charts to estimate the expected date of discharge preparing the caregivers physically, psychologically, emotionally, and financially. Because of this unpreparedness for discharge, over 90% of the caregivers who were admitted in A.I.C Mission hospital were financially constrained unlike their colleagues who were admitted in Kapkatet sub-County Hospital. Caregiver B a father made it clear that when they were released home, he had mixed feelings of happiness and sadness at same time because of the fear of unknown. At the same time, mother O said that she was not prepared to go home since she was not told early enough to prepare herself financially and even emotionally and it was her wish that she could have been prepared before the material day of discharge.

After discharge, instructions on the follow-up clinics were so scarce that the caregivers were left wondering how long their preterm babies would be followed up in POPC. When attending paediatric outpatient clinics (POPC), they expected cheerful, sympathetic, and encouraging health caregivers who could not shout at them revealing the poor communication skills of the health caregivers as pointed out by Petty et al., (2021); Wigert et al., (2014) studies. One caregiver bitterly narrated how she was rudely addressed to as she attended the paediatric out-patient clinic. In summary, caregivers of preterm babies were in support of training the health caregivers on communication skills, formation of peer-support groups at the community level, financial support programs, and clear follow-up procedures. Every one of these findings was the same as those discussed in Lakshmanan et al. (2019); Lakshmanan et al., (2017); and Reymundo et al. (2019).

5.3 Conclusion

Preterm babies are not only a blessing to the family but they can also be a challenge to the family. Caregivers of preterm babies experience both good and bad experiences not

only while in the hospital but also at home after discharge. The good experiences majorly include the financial, psychological, physical and emotional support given to the caregivers by the relatives, peers, and the church. Fathers (men) played a key role in supporting their families (wives and children) in all aspects of life. The bad experiences were as follows; working round the clock, having fear of the unknown, and stigmatization. These affected every caregiver as they were taking care of their preterm babies at home.

5.4 Recommendations

5.4.1 Policy Recommendations

The following are the policy recommendations:

i. The patient-oriented care given at the hospital level to be in-cooperated with community-oriented care for efficient, effective, and wholesome care of preterm babies and their caregivers in and outside the hospital.

ii. To reduce the stigmatization of the caregivers of preterm babies, there is a need to create awareness in the community concerning the care of preterm babies and their caregivers.

iii. Healthcare workers are to be trained in communication skills and community follow-up of caregivers of preterm babies and their babies.

iv. The hospitals collaborate with the communities to create support groups for the caregivers of preterm babies in the community

v. The Ministry of Health to make policies regarding the follow-up of preterm babies and their caregivers to the community.

vi. Men (fathers) to be involved in the care of the preterm babies while in hospital and after discharge.

5.4.2 Recommendations for Further Studies

i. There is a need for a country-wide study to be conducted for the findings to be generalized and this study should include caregivers whose preterm babies were born outside the hospital setting.

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APPENDICES

Appendix I: Semi-Structured Interview Guide

Section A: Introductory statement, greeting and filling of consent form.

and thanks for having you here and for agreeing to be interviewed today. Just to remind you that the purpose of this study is to find out caregivers' experiences in caring for a preterm baby at home. This interview guide contains open ended questions that the researcher will refer to from time to time. You are expected to kindly provide genuine answers to the questions. The information you provide is confidential and will be used only for the purposes of this study. If you have any question, do not hesitate to ask the person conducting this interview. Although your cooperation and participation until the completion of the interview is necessary for the successful completion of the study, please be reminded that you can opt out at any time. You will not be penalized in anyway by refusing to participate. You will need to sign the attached consent form before we start the interview if you agree to be part of this study.

Section A: Background information of participants

Can you please introduce yourself?

1. Age
2. Marital status: married / cohabitation.
3. Number of Children
4. Educational level
5. Occupation
6. Religion
7. Ethnicity
8. Birth weight of baby

9. Gestational age at birth

10. Length of hospital stay

Section B: Mothers' Experiences

1. Please tell me about your experiences in caring for a preterm/premature baby at home. Can you describe what is has been like caring for a preterm baby since you got home from hospital?

Probes

•Can you share what your typical day is like?

•How long does it take you in caring for the baby on daily basis?

•Tell me how you feed your baby.

•How do you make sure your baby is safe and protected?

•How do you generally care for yourself and other children?

•In what ways have you been affected?

•How have your significant others (family and friends) supported you?

•Describe any other experiences that I have not asked about that you feel is important to note in this study

Appendix II: Questionnaire

Introductory statement

Hello and thanks for agreeing to be interviewed today. Just to remind you that the purpose of this study is to find out caregivers' experiences in caring for a preterm baby at home. This interview guide contains open ended questions that I will refer to, from time to time. You are expected to kindly provide genuine answers to the questions. The information you provide is confidential and will be used only for the purposes of this study. If you have any question, do not hesitate to ask. Although your cooperation and participation until the completion of the interview is necessary for the successful completion of the study, please be reminded that you can opt out at any time. You will not be penalized in anyway by refusing to participate.

Section A: Background information of participants

1. Age
2. Marital status: Married ☐ Single ☐
3. Number of children
4. Education level: Primary ☐ Secondary ☐ College ☐
5. Occupation: Employed ☐ Unemployed ☐
6. Religion
7. Birth weight of the baby
8. Gestational age at birth
9. Length of hospital stay

Section B: Caregiver's Experiences

1. Please tell me about your experiences in caring for a preterm/premature baby at home during the first six months post discharge. Can you describe how it has been like caring for a preterm baby since you got home from hospital? *Tafadhali nieleze kuhusu uzoefu wako wama lezi ya mtoto wako miezi sita baada ya kutoka hospitalini. Waweza kueleze ajinsi ambavyo malezi ya mtoto yamekuwa tangia utoke hospitali?*

Probes

- Can you share what your typical day is like? *Siku yako alisihuwa je?*
- How long does it take in caring for the baby/babies on daily basis? *Katika maisha ya kila siku, ukuchu kuamdagani kumtunza mwanao/wanao?*
- Tell me how you fed your baby/ babies. *Hebu nieleze jinsi ulikuwa ukimlisha mtoto /watoto wako?*
- How did you make sure your baby/babies is safe and protected? *Ulihakikishaje kuwa mtoto /watoto wako ako/wako salama naana/wanaulinzi wa kutosha?*
- How did you generally care for yourself, spouse, and other child/children? *ulijitunzaje, nakumtunza mkeo/mmeo, namtoto/watoto?*
- In what ways have you been affected? *Je, umeadhirika kwa njiagani?*
- How have your significant others (family) supported you? How? Financially/socially. *Je, wapendwa wako (familia) wamekuwa wamsaada? Kivipi? Kifedha/mahusiano*
- What role did the community (friends, peers, and neighbors) play in taking care of your preterm baby/babies? *Ni jukumu gani jamii (marafiki, wenye watoto kama wenu, na majirani) walichukuwa katika malezi ya mtoto/watoto wako/wenu?*

2. Hospital experiences

- Please describe your experience in the neonatal care unit. *Tafadhal ielezea uzoefu wako ulipokuwa hospitalini.*
- How prepared were you for discharge and transitioning to home care for your preterm baby? *Je, ulikuwa umejianda aje kuhusu kwenda nyumbani nakutunza mtoto wako?*

- Please describe your experience over the first six months post discharge at the outpatient follow-up clinic. *Tafadhali elezea uzoefu wako ulipokuwa ukitembelea kliniki miezi sita ya kwanza baada ya kutoka hospitali.*
- Describe any other experiences that I have not asked about that you feel is important to note in this study. *Elezea mambo mengi ambayo sijaulizia lakini unahisi kwamba nimuhimu kwenye utafiti huu.*

Appendix III: Adult Informed Consent Form

Study Title: Post-Discharge Experiences Among Caregivers of Preterm Babies In Kericho County, Kenya.

PI: Abiuty Omwenga Omweri. Affiliated Institution: Kabarak University

Introduction

You are invited to participate in this research study being undertaken by the above-named researcher. This form will help you gather information about the study so that you can voluntarily decide whether to participate or not. You are encouraged to ask any question regarding the research process as well as any benefit or risk that you may accrue by participating. After you have been adequately informed about the study, you will be requested to either agree or decline to participate. Upon agreeing to participate in the study, you will be further requested to affirm that by appending your signature/thumbprint on this form. Accepting or declining to participate in this study does not in any way waive the following rights which you're entitled to:

a. Voluntary participation in the study;
b. Withdrawing from the study at any time without the obligation of having to give an explanation and;
c. Access to services which you're entitled to.

A copy of this form will be provided to you for your own records

Should I continue YES/NO_____

This study has been reviewed and approved by Kabarak University Research Ethics Committee (KUREC)

What is the Purpose of the Study?

The main reason for conducting this study is to answer the following question:

What challenges do caregivers of preterm babies have at home after discharge from a newborn care unit (NCU) in A.I.C Litein Mission and Kapkatet Sub-County hospitals?

(In order to answer these research questions, you are requested to voluntarily answer questions you will be asked)

Who can Take Part in the Study?

Inclusion criteria – parents of preterm babies

Exclusion criteria: -

a) All caregivers of preterm babies from other counties who would like interviews conducted at their homes.
b) Caregivers of preterm babies with gross congenital anomalies

The sample size will be determined ones saturation of the information given has been achieved.

This is what is going to happen once you have agreed to participate in the study:

First, the interview will be anticipated to last between 40 – 60 minutes.

Secondly, the researcher and where necessary a qualified and well-trained interviewer will ask you questions in a private place where you will feel comfortable. In case there is any question you feel uncomfortable responding to, you will not be coerced to respond. The questions will be on the following areas:

a) Hospital stay and transition to home care
b) Home care and the support from the community
c) Outpatient follow up clinics

There will be no benefits or risks involved for you if you agree to participate.

Privacy & Confidentiality

The in-depth interviews will be conducted preferably at outpatient clinics in Litein Mission and Kapkatet Sub-county hospitals or at the participant's preferable place within

the locality of the two research sites. The selected places of interviews will be quiet, comfortable, and only accessible by the researcher and the participant so as to ensure privacy and confidentiality.

The voice recorder and all data collected will be under lock and key accessible by the researcher only. The voices will be distorted and all identifiers removed by the researcher for confidentiality purposes. All the data will be kept for five years after which it will be discarded.

In case you aren't comfortable answering any of the questions during the interview because of feeling embarrassed or uncomfortable, it will be within your rights to decline. Otherwise every measure has been taken to ensure that the interview is conducted in a private area with minimal to no interference so that you feel comfortable.

What benefits are you going to accrue by participating in the study?

The study will help to direct resources that will enable the follow up of preterm babies and their caregivers all the way to the community and this in return will help reduce the deaths and morbidities related to prematurity in Kericho County.

Cost of participating in the Study?

There is no cost to be incurred for your participation; however, if you are to travel specifically for the interview, your fare will be reimbursed.

In the event that you need further clarification or questions regarding your participation in this study feel free to contact the PI (0722456469). In case of concerns regarding your rights and/or obligations as a research participant do not hesitate to contact the secretary, KUREC on {*KUREC contact*}

The decision on whether to participate or not is absolutely voluntary. You will be free to withdraw from the study at any point during the study without providing any explanation.

How Will the Findings of this Study be Communicated or Shared?

The findings of this study will be communicated to the relevant departmental heads of A.I.C Litein Mission Hospital and Kapkatet County Referral Hospital by the researcher who will in return inform the hospitals' administration. The hospitals administration will let the Ministry of Health in Kericho County know the findings and the recommendations for it to take action where necessary. It will also in inform the relevant institutions on the specific needs of parents of preterm babies once they are discharged home and give recommendations on the structures to be put in place for follow up. The study will help to direct resources that will enable the follow up of these clients all the way to the villages and this in return will help reduce the deaths and morbidities related to prematurity in Kericho County.

Statement of Consent

I have comprehensively read the consent form or/the information has been comprehensively read to me by the researcher. I have understood what the study is about and all the questions and concerns that I had have been responded to in a clear and concise. The study benefits and foreseeable risks have been explained to me. I totally understand that my decision to participate in this study is voluntary and I have the right to withdraw at any point during the study.

I freely consent to participate in this study

Signing this form does not in any way imply that I have given up the rights am entitled to as a participant

I agree to participate in this research YES_____ NO_____

Participant's Name

Participant's Signature/Thumb print_____ Date_____

Appendix IV: Codes

1. People see you as a failure…
2. You always ask yourself, why is she so tinny?
3. What did I do wrong?
4. Sometimes when I approached someone with my child, the person will leave to avoid me and my child (avoidance of both mother and baby)
5. That is so hurting and discouraging if not disappointing or inhuman
6. The child is innocent but an adult doesn't understand it
7. My friends asked me, what kind of a woman are you giving birth to a very small baby?
8. He is too small even my shoe is big; his size is that of a rat
9. I didn't have that courage to carry our baby to the clinic since I feared what our neighbours would say about the size of our child-fear of stigmatization
10. It can slip out of the blankets without her noticing
11. Because my child was too small, I could not attend meetings
12. I used to lock myself inside because other women (mothers) used to say that this child is too small.
13. Nobody came to my house for a cup of tea
14. You feel bad
15. I was scared/ this scared me a lot
16. I was not ready to go home because you see, I will be alone
17. No nurses or doctors for support
18. You need more time,
19. You are forced to stop every other chore because you don't know what will happen to him

20. I wonder whether he will speak, walk or he will be disabled
21. I could sneak from work so as to keep checking if he is okay
22. Something wrong might happen to her
23. Wherever I went, I took her along with me since I could not trust anyone that could take care of her as I do
24. This child probably needed 15 to 20 hours a day for proper care
25. My mother took leave to take care of me and my son
26. Was an uphill task that needed sacrifice and dedication.
27. Feel fatigued and so tired that during the day I could fall asleep while seated
28. Having a premature baby takes all your energy and time
29. They feed my child as I go to rest
30. My mother in-law used to cook, wash all the clothes, mob the floor.
31. My sisters took turns to do the cooking, cleaning of the house, washing the dishes, etc
32. My husband would wake up early, do all the cleaning in the house etc
33. He was not only my husband but my counsellors and everything in this world
34. My church members visited me, prayed for the good health of my son and protection
35. They stood by my side (church members)
36. Church members were my pillar when my faith was weak
37. She told me not to fear, her child was even smaller than mine
38. This encouraged me
39. I expected the staff in NCU to be understanding
40. I didn't know how to do it and I expected to be directed
41. I was harassed the first time with nurses
42. They talk arrogantly

43. I come from home stressed expecting to get someone who would talk to me nicely but guess what!
44. It is heart breaking
45. Take hid of what the mother says, the doctor should listen instead of brushing it off
46. To be prepared for discharge
47. Be told in advance
48. Had mixed feelings

Grouped Codes

Stigmatization

1. People see you as a failure...
2. My friends asked me, what kind of a woman are you giving birth to a very small baby?
3. He is too small even my shoe is big; his size is that of a rat
4. It can slip out of the blankets without her noticing
5. You feel bad

Low self-esteem

1. You always ask yourself, why is she so tiny?
2. What did I do wrong?
3. I didn't have that courage to carry our baby to the clinic since I feared what our neighbours would say about the size of our child

Social Isolation

1. Because my child was too small, I could not attend meetings
2. I used to lock myself inside because other women (mothers) used to say that this child is too small.
3. Nobody came to my house for a cup of tea

4. You feel bad

Fear of unknown

1. I was scared/ this scared me a lot
2. I was not ready to go home because you see, I will be alone
3. No nurses or doctors for support
4. You are forced to stop every other chore because you don't know what will happen to him
5. I wonder whether he will speak, walk or he will be disabled
6. I could sneak from work so as to keep checking if he is okay
7. Something wrong might happen to her
8. Wherever I went, I took her along with me since I could not trust anyone that could take care of her as I do

Care round the clock

1. You need more time
2. You are forced to stop every other chore because you don't know what will happen to him
3. This child probably needed 15 to 20 hours a day for proper care
4. Was an uphill task that needed sacrifice and dedication.
5. Feel fatigued and so tired that during the day I could fall asleep while seated
6. Having a premature baby takes all your energy and time
7. Hospital Stay (NCU)
8. I expected the staff in NCU to be understanding
9. I didn't know how to do it and I expected to be directed
10. I was harassed the first time with nurses
11. They talk arrogantly

Date of discharge

46. To be prepared for discharge

47. Be told in advance

48. Had mixed feelings

Follow up clinics (POPC)

1. I was harassed the first time with nurses
2. They talk arrogantly
3. I come from home stressed expecting to get someone who would talk to me nicely but guess what!

It is heart breaking

1. Take hid of what the mother says, the doctor should listen instead of brushing it off Community
2. Sometimes when I approached someone with my child, the person will leave to avoid me and my child
3. That is so hurting and discouraging if not disappointing or inhuman…
4. The child is innocent but an adult doesn't understand it
5. My friends asked me, what kind of a woman are you giving birth to a very small baby?
6. He is too small even my shoe is big; his size is that of a rat

Family Members' Support

1. My mother took leave to take care of me and my son
2. My mother in-law used to cook, wash all the clothes, mob the floor.
3. My sisters took turns to do the cooking, cleaning of the house, washing the dishes, etc
4. My husband would wake up early, do all the cleaning in the house etc

5. He was not only my husband but my counsellor and everything in this world

Church members' support

1. My church members visited me, prayed for the good health of my son and protection
2. They stood by my side (church members)
3. Church members were my pillar when my faith was weak

Peers' support

1. She told me not to fear, her child was even smaller than mine
2. This encouraged me

Appendix V: KUREC Approval Letter

KABARAK UNIVERSITY RESEARCH ETHICS COMMITTEE

Private Bag - 20157
KABARAK, KENYA
Email: kurec@kabarak.ac.ke

Tel: 254-51-343234/5
Fax: 254-051-343529
www.kabarak.ac.ke

OUR REF: KABU01/KUREC/001/01/04/23 **Date: 4th April, 2023**

Abiuty Omwenga Omweri,
Reg. No: GMMF/M/2691/09/18
Kabarak University,

Dear Abiuty,

RE: POST-DISCHARGE EXPERIENCES AMONG CAREGIVERS OF PRETERM BABIES IN KERICHO COUNTY, KENYA.

This is to inform you that ***KUREC*** has reviewed and approved your above research proposal. Your application approval number is ***KUREC-010423.*** The approval period is ***4/04/2023 – 4/04/ 2024.***

This approval is subject to compliance with the following requirements:

i. All researchers shall obtain an introduction letter to NACOSTI from the relevant head of institutions (Institute of postgraduate, School dean or Directorate of research)
ii. The researcher shall further obtain a RESEARCH PERMIT from NACOSTI before commencement of data collection & submit a copy of the permit to **KUREC.**
iii. Only approved documents including (informed consents, study instruments, MTA Material Transfer Agreement) will be used
iv. All changes including (amendments, deviations, and violations) are submitted for review and approval by ***KUREC***:
v. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to ***KUREC*** within 72 hours of notification;
vi. Any changes, anticipated or otherwise that may increase the risk(s) or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to ***KUREC*** within 72 hours;
vii. Clearance for export of biological specimens must be obtained from relevant institutions and submit a copy of the permit to KUREC;
viii. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal and;
ix. Submission of an executive summary report within 90 days upon completion of the study to ***KUREC***

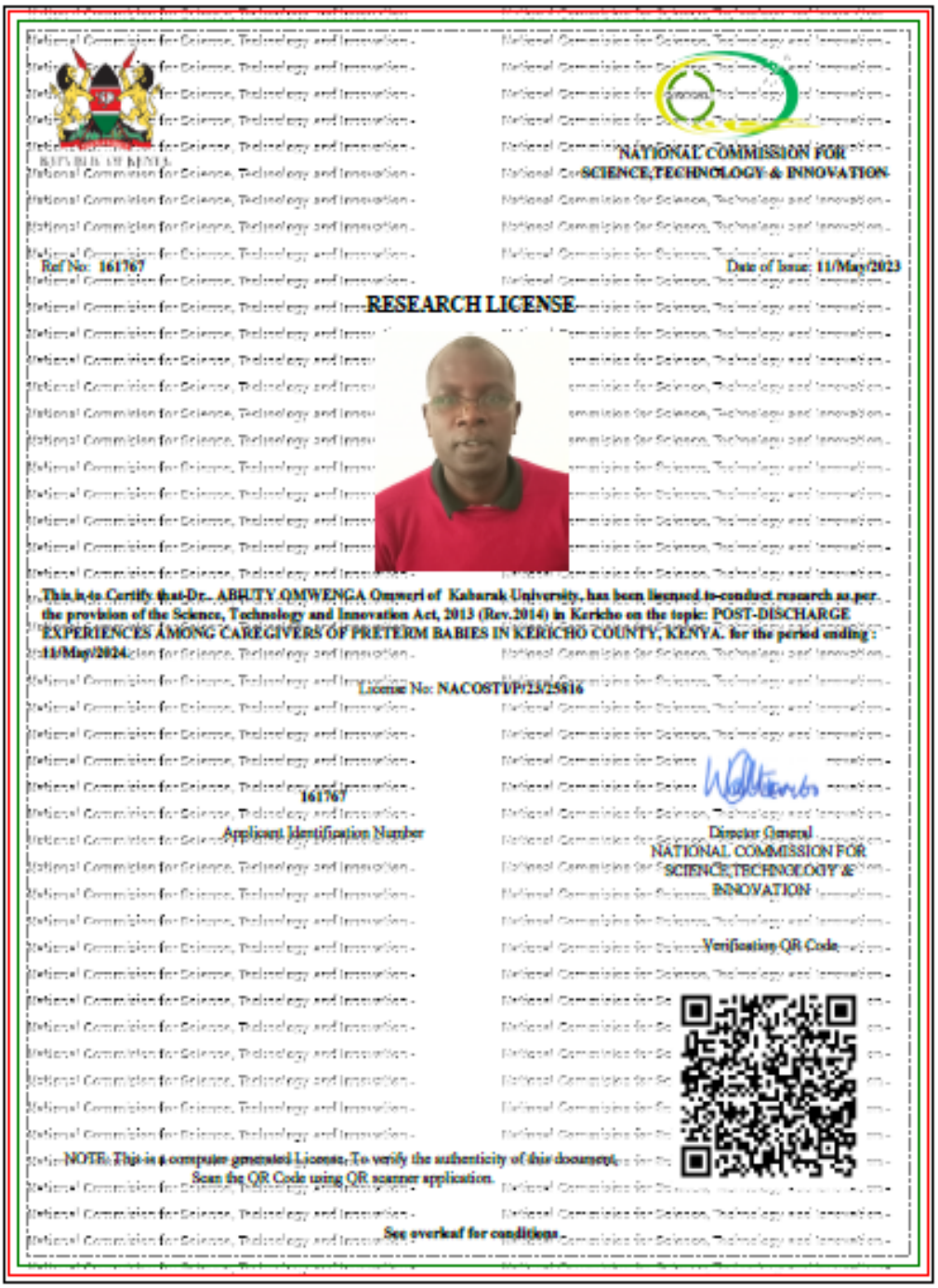
Sincerely,

KABARAK UNIVERSITY INSTITUTIONAL RESEARCH ETHICS COMMITTEE 05 APR 2023 APPROVED P.O. Private Bag - 20157 KABARAK

Prof. Jackson Kitetu PhD.
KUREC-Chairman

Cc Vice Chancellor
DVC-Academic & Research
Registrar-Academic & Research
Director-Research Innovation & Outreach
Institute of Post Graduate Studies

Appendix VI: NACOSTI Research Permit



NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: 161767

Date of issue: 11/May/2023

RESEARCH LICENSE

This is to Certify that Dr.. ABRUTY OMWENGA Omweri of Kaburak University, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Kericho on the topic: POST-DISCHARGE EXPERIENCES AMONG CAREGIVERS OF PRETERM BABIES IN KERICHO COUNTY, KENYA. for the period ending : 11/May/2024.

License No: NACOSTI/P/23/25816

161767

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

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See overleaf for conditions

Appendix VII: Evidence of Conference Participation

University of Kabianga

INNOVATION AND EXCELLENCE

CERTIFICATE OF PARTICIPATION

THIS CERTIFICATE IS AWARDED TO

Dr. Abiuty Omweri

for participating in the 3rd University of Kabianga Multidisciplinary Conference held at the University of Kabianga Main Campus between 27th and 28th September, 2023.

Theme: Innovation and Practices for Research and Sustainable Development Goals in the 21st Century

Prof. Maurice Oduor
Deputy Vice-Chancellor Planning
Research and Development.

Prof. Joash Kibett
Chairperson, Conference Organising Committee

ISO 9001:2015

Appendix VIII: List of Publication

JOURNAL OF CLINICAL CARE AND MEDICAL ADVANCEMENT

https://doi.org/10.58460/jcma.v1i01.74

Open Access

ORIGINAL ARTICLE

MJM BIOLABS

Caregivers' Experiences in Providing Home Care for Preterm Infants during the Initial Six Months Post-Discharge from the Neonatal Care Unit

Abiuty OMWENGA OMWERI[*1], MATTHEW LOFTUS[1], Pamela KIMETO[1]

[1] *School of Medicine & Health Science, Department of Family Medicine, Kabarak University, P.O BOX private bag 20157, Nakuru, Kenya.*

[*]Corresponding Author: aomwenga@kabarak.ac.ke

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ABSTRACT

Nearly 15 million preterm babies are born yearly, worldwide. Out of which 1 million succumb to the complications directly related to premature birth. In Kenyatta National Hospital the prevalence of preterm birth is 18.3% while the mortality rate of preterm babies under 5 years is about 7% per year countrywide. Many studies that highlight the experiences of caregivers of preterm babies have been conducted in neonatal care units and few outside the hospital setting. A majority of these studies have been done in developed countries. However, in Kenya, there is a scarcity of such studies exploring the experiences of caregivers of preterm babies not only in neonatal care unit (NCU) but also after they have been discharged. This study aimed to evaluate the experiences caregivers of preterm babies face at home in the first 6 months post-discharge. This was a phenomenological study. Sixteen preterm caregivers were purposively sampled from Litein Mission and Kapkatet County hospitals' outpatient clinics. Ethical approval was sought from KUREC and a Research Permit from NACOSTI. Interviews were conducted using a semi-structured interview guide at the participants' convenience. The interviews were audio-recorded, transcribed verbatim, and analysed thematically to identify sub-themes and key themes. Majority of the caregivers faced discrimination from the community; they were anxious and worried about the welfare of their babies as they were working throughout the day to keep them safe from harm. The caregivers face the following challenges: (a) stigmatization and fear of unknown (b) working round the clock (c) Support given to Caregivers. To overcome the above challenges, they received support from family members, peers, and church members. We conclude that caregivers may have a myriad of negative experiences at home. We recommend that healthcare givers be incorporated into community-oriented care to optimize and improve the well-being of the infants.

Keywords: Caregivers, Post-Discharge, Premature Birth, Preterm Babies