UNIVERSITY *of* **RWANDA**

Perspectives of caregivers on home transition of premature infants assessed by a post-discharge telephone call in two Rwandan teaching hospitals (CHUK and RMH)

A dissertation submitted in partial fulfilment of the requirements for the degree of Master of Paediatrics and Child Health

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DECLARATION

I declare that solely myself have composed this thesis and that it has not been submitted, in whole or in part, in any previous application for a degree, except where states otherwise by reference or acknowledgment, the work presented is entirely my own.

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Date: 30/06/20 6:47 PM

DEDICATION

I dedicate this work to:

My family,

The entire team of pediatrics residents,

My pediatrics mentors, and RMH and CHUK's Neonatology departments.

ACKNOWLEDGEMENTS

Study title:

Perspectives of caregivers on home transition of preterm infants assessed by a post-discharge telephone call in two Rwandan teaching hospitals (KUTH and RMH)

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Abstract

Background/Introduction

Many studies done in countries with limited resources focus on the hospital outcomes of the preterm infants. However, continuity of care at the community level, once these babies are discharged as well as early and regular follow up is also needed in order to improve outcome of these infants. Follow up by phone calls have been used for early and long-term follow in middle and high incomes nations. The aim of this study was to use a post-discharge telephone call to better understand the transition to home care practice of families caring for Preterm Infants.

Methods

This is a prospective cohort study where caregivers of preterm infants discharged during a six-months period were interviewed on the phone within one to three weeks after discharge; the data were analyzed by to SPSS. Categorical data were used for frequencies and percentages in tables, and median or SD for continuous data. Chi-square test and logistic regression were used to study the relationships between the outcomes and their possible predictors. Statistical significance for associations was taken at the level $p < 0.05$.

Results:

One hundred and ten newborns were enrolled in our study. Out of these, 86 (78.2%) of the participants were successfully interviewed on phone within one to three weeks post-discharge while 24 (21.8 %) were not reached despite providing at least three phone numbers. The majority 84 (97.7%) reported their newborns to be alive, while two (2.3%) passed away and 6 (7%) reported to be readmitted within 2 weeks after discharge. Only two third (66.3%) of these infants continued to breastfeed exclusively while 29 % were kept on formula and breast milk, Only 86% of parents reported continuing KMC but only for a mean of 3.5 hours/ day. Many 72 (83.7%) of them kept their infants on vitamin D and irons supplementation, 48 (55.8%) of them reported their infants to be vaccinated while 38(44.2%) of them were not vaccinated. Less than half (48.7%) had been visited by a community health worker Nutrition and feeding practice, vaccination and KMC were among the challenges that were addressed on phone call. Living far away from the referral hospital was associated with poor follow up with a pediatrician (OR: 4.3; 95%CI: 1.7-11.2; p=0.002) or pediatrician review (OR: 4.3; 95%CI: 1.7-11.2; p=0.002).)

Conclusion

Post-discharge phone calls can be used in the post-discharge follow up of the preterm infants to address some parents' questions and challenges. Gaps in transitioning these preterm infants to a home setting must be improved, particularly vaccination, follow up by CHW and with healthcare providers and adherence to discharger instructions and recommendations.

Keywords (MeSH-terms)

Glossary of Terms

C/S:	Cesarean section
CHBI:	community health based insurance /Mutuelle de santé
CHD:	Congenital heart disease
CHW:	Community health workers
CMHS:	College of medicine and health sciences
DH:	District hospital
DHS:	Demographic and Health Survey
EDD:	Estimated date of delivery
ELBW:	Extremely lower birth weight (<1000g)
GA:	Gestational age
IRB:	Institutional Review Board
IVH:	Intraventricular hemorrhage
LBW:	Low Birth Weight (<2500g)
LMP:	Last menstrual period
MDG:	Millennium development Goals
MOH:	Ministry of health
NICU:	Neonatal intensive care unit
OPD:	Outpatient department
PMGA:	Postmenstrual gestational age
PMT:	Prematurity
RMDC:	Rwanda medical and dental council
RMH:	Rwanda military hospital
ROP:	Retinopathy of prematurity.
SDG:	Sustainable development goals
SPSS:	Statistical package for social sciences.
SVD:	Spontaneous vaginal delivery
UR:	University of Rwanda
UTHB:	University Teaching Hospital of Butare
UTHK:	University Teaching Hospital of Kigali
VLBW:	Very low birth weight (<1500g)
VLBW:	Very Low birth weight (1500 grs -2500 grs)
WHO:	World Health Organization

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Though studying the association between socio-demographic factors and follow up outcome was not an objective of this study, a chi-square test was done and revealed no statistical significance on the association of participant's level of education and follow up to KMC or vaccination practices of the preterm infants (Table 7)...26

CHAPTER

I: INTRODUCTION

1.1. Background

Globally, in 2015 the under-five mortality was estimated at 5.42 million with 45.1% of these children dying in the neonatal period (death within the first 28 days of life) and with complications of prematurity being the leading cause of deaths. Prematurity is defined as birth at less than 37 weeks of completed of gestation weeks, and causes, worldwide, an estimated annual death of 1.055 million (95% uncertainty range (0.93-1.179)). In sub-Saharan Africa prematurity and its complications comes on the second place as the cause of under 5 years death after pneumonia (1,2).

The last Rwanda DHS (2014-2015) revealed that 66% of infantile deaths were due to neonatal death and that neonatal mortality is still high at 20 per1000 live births (3) .The third SDG has the intension of reducing the neonatal mortality globally up to less than 12 per 1000 live births for each country (4). Preterm infants are not only at risk of early complications, but once they survive the neonatal period, are particularly at risk of late complications (such as recurrent or severe respiratory infections, failure to thrive, anemia of prematurity and neurological and cognitive delay) and of frequent hospital readmission(5,6). In Malawi, in a long term cohort study follow-up they stressed that in first year of life, the mortality rate of preterm infants in the post-discharge period is estimated to be double of term newborn (7.7% Vs. 4%) (7).

   Some of these complications may be prevented through early and effective maternal discharge education which includes encouragement to follow-up, the involvement of the caregivers in continuing practices such us kangaroo mother care and emphasizing adherence to post-discharge recommendations (8). It is also essential to consider discharging infants who have attained a certain weight, as a lower weight on discharge is associated with higher mortality (9). For instance, one study done in Uganda found a mortality rate of 68.7% during the first month post-discharge when the weight on discharge is between 1200gr -1500 gr(10), Of note, in the

neonatal units at University Teaching Hospital of Kigali (CHUK)and Rwanda military hospital (RMH), preterm infants are not discharged before reaching 1500g.

The perinatal, neonatal, but also the post-neonatal period are important for preterm infants. A study done in South Korea showed that pre-discharge education and phone calls based follow-up can increase the compliance to the postneonatal follow-up, leading to both improved early and late outcomes (11). Mother whose preterm infants are born prematurely may not feel ready for their infants care and this stressful period can have potential impact on the attachment of the mother to her premature infant (12,13). A study done in Iran demonstrated that maternal level of education and low socio-economic status are potential factors that affect the adherence to follow-up. A comprehensive pre-discharge education of the caretakers on early long term complication of prematurity may also increase post-discharge follow-up (14). In a randomized case-control study, it was shown that a phone call follow- up and phone consultation reduces the frequency of readmission of preterm infants and is associated with improved duration of exclusive breastfeeding. This study found that four and six weeks after an initial phone counseling there is reduction of frequencies of readmissions in the interventional group. After phone call counseling at the 4th, 6th and 12th weeks post-discharge, the rate of readmission in the intervention vs. the control group was 26% vs.52%, 8% vs.24% and 0% vs. 7% respectively (12).

Recommendations given on discharge of preterm infants include iron and vitamin D supplementation, nutritional recommendation, and follow-up recommendation for neuro-development assessment, for weight check and for retinopathy of prematurity screening and treatment. Preterm infants are at risk of iron deficiency and should be on iron at discharge; It has been shown that the earlier (once enteral feed reach 100ml/kg/day) iron supplement is initiated, the more it has effect on long-term outcomes; (15) The Rwanda National protocol recommend to supplement elemental iron orally at 2-4 mg/kg/day up to at least 6 months (16,17). Prematurity can also lead to osteopenia and generally the lower the gestational age at birth, the higher the risk of developing rickets; Studies proved that early Vitamin D of at least 800 IU supplementation significantly prevents a decrease in bony density and linear growth impairment (18).

The Rwanda neonatology protocol (1st and 2nd edition, 2014) also recommends that infants born with less than 2kg or at less than 35 weeks gestation should be followed up in the outpatient department, either at nearest district hospital or health center within 2 weeks post-discharge(19).

In addition, in their 1st week after discharge, the community health worker in charge of maternal and newborn health is supposed to visit the preterm infants for assessment of danger signs (20)

The experience of pediatricians and the neonatologist at CHUK and RMH is that only few of the preterm infants who are discharged from the neonatology unit actually return for follow-up. Many of these preterm infants live far away and face significant challenges, with many whose parents report facing financial challenges after having exhausted their funds while they were hospitalized in the neonatology unit.

Our study aims to outline and better understand the post-discharge transition to home of these preterm infants and the challenges encountered by the parents who care for them.

1.2. Problem statement /Rationale of the study

Despite some global strategic measures undertaken over last decades, prematurity and its associated early or late morbidity and mortality is still remaining the same or is even slightly increasing every year(21). Mothers with preterm infants need to be prepared prior for transition to home care as this period can be associated with parental anxiety and stress especially when the caregiver is not ready to be engaged in outpatient transition care (22,23).

As in many low resource countries, well established long term systematic NICU follow-up clinics with early intervention for risk infants don't exist in Rwanda (24). In the neonatology units at CHUK (university teaching hospital of Kigali) and (RMH) Rwanda military hospital, many preterm infants are now being discharged once they reach full feeds; either on bottle feeds only or combined with breastfeeding. Prior to discharge, recommendation in terms of nutrition, warning signs of infection, follow-up and micronutrients supplementation are usually given to the main caregiver. However, preterm infants are fragile and often have complex medical needs that can be difficult to be handled by the parents   especially in limited resources settings where the continuity of care is exclusively done by parents. There are, as far as we know, no local published studies describing how this transition to home happens and whether parents are able to understand specific needs such as micronutrients supplementation, importance of ROP screening, immunization etc. In order to optimize transition to home and appropriate home care, we need to better understand the experience of parents who are discharged with preterm infants. A follow-up phone call done after discharge from neonatology will help us not only better understand these challenges but potentially help the mothers to problem solve some of these on the phone.

1.3. RESEARCH AIMS AND OBJECTIVES

1.3.1. Research aim

The overall aim of this study is to better understand the transition to home of preterm infants being discharged from the neonatology units at CHUK and RMH.

1.3.2. Objectives

The objectives of this research project are

1. To assess parents' practices of post neonatal discharge care of preterm infants.
2. To outline the barriers and challenges faced by these caregivers in caring for their newborn after discharge
3. To evaluate the feasibility and perceived usefulness of conducting post-discharge phone calls based follow up.

CHAPTER II: LITERATURE REVIEW

We searched PubMed, Cochrane and Research Gate for studies that looked at the challenges encountered by parents when transitioning their preterm infants from neonatology units to home in Sub-Saharan Africa, as assessed by phone calls. We found no published studies. We found a few studies that focused on post-discharge outcomes (mortality and morbidity) of preterm infants(24,25). We also went through the reference list of these studies to identify other potentially relevant studies. The only study found to be done in limited resources countries, in Malawi where the phone call follow up was used for post-discharge of the critically ill children in rural clinics, this study concluded that if nationwide phone coverage is adequate this type of follow up may be used as health survey assistance.(26) There were some studies found where phone calls were used to assess challenges encountered by parents caring for older children with complex chronic diseases who were discharged from a pediatric inpatient unit, but these studies were done in high-resource countries(12,22,27). The most relevant published studies are summarized below.

Contrary to resource-rich nations, well-established longitudinal post-discharge follow-up and home-based care are often not available in resource-limited countries (24). Transition of care from hospital to outpatient care can be a challenge to patients or their caregivers and may be further exacerbated by poor communication or misunderstanding of the discharge instructions. In the US, in children discharged from a general inpatient pediatric unit, a follow-up phone call was able to address frequent issue related to transition to home and outpatient care. However, the statistical significance of this study was low in terms of detecting the reduction of hospital readmission rates, patients satisfaction or ER consultation (28).

Many studies in developed countries aimed to assess maternal experience of premature infant in terms of feeding, maternal anxiety and readiness to outpatient transitional care. For instance, a study done in Italy showed that the rate and severity of maternal anxiety and depression is associated with the severity of prematurity and with inaccurate communication with the health care team(29).

A mixed-methods study conducted in Saint Petersburg children's hospital, found that out of 32 mothers assessed for maternal experience with post-discharge care of their preterm infant, 75% of caregivers reported being comfortable caring for their preterm infants. However, frequent themes reported were parental concerns about feeding and behavioral problems and infants and

preterm infants needing special individualized care(27). A systematic of articles focused on transition to home of preterm infants and how the safe continuity of care for the premature infant can be ensured showed that evidence-based programs can help families with a premature infant improve the transition from hospital to home. One of the five components identified was improved communication between the healthcare provider and the family at home and that availability of the healthcare team via telephone, telephone conference or pager were effective in reducing anxiety and improving coping of the parents (30).

A study conducted in Iran to compare outcomes of preterm infants whose mother received follow-up by phone call at four weeks, six weeks and 12 weeks after discharge to those who didn't. Fifty mothers were randomized to receiving a phone call lasting 10 -15 minutes and compared to 50 who didn't. This study found a reduction in readmission rate weeks and 0% vs. 14% at 12 weeks. 0% at four weeks, 8% Vs. 30% at six of 24% Vs. 5(12).

Another Iranian study aimed to assess the predictors of follow-up and early intervention services post–discharge. In this study, 119 mothers of preterm infants admitted in a neonatology unit were enrolled. After filing a form of maternal demographic data on discharge, they received also a post hospital discharge phone call to assess follow-up predictors. Only 65% of these mothers brought their infants for follow-up and a multivariate analysis revealed that low maternal education, unawareness of the post-discharge follow-up, lack of referral by physician and short NICU admissions were factors associated with poor follow-up (14).

Many studies in low-income regions focus on post-discharge morbidity and mortality of premature newborns. For instance in Mulago Hospital in Uganda in a prospective cohort study where 168 preterm infants enrolled for 8 months follow-up, the post-discharge mortality rate was19.5% and two thirds of these deaths occurred during the first month post-discharge. The mortality was particularly high when the infants were discharged before reaching 1.200 gr (9). However, not only is mortality high in these patients, but morbidity can also be quite significant. A cross-sectional study done in rural in Rwanda (Rwimkwavu DH) from 2011-2013 on 158 preterm infants found that 46.5% reported to have feeding issues, 39.5% reported symptoms and signs of anemia, 78.3% were stunted, 8.8 % were wasted and 67.4% had abnormal development screening (24).

CHAPTER III: MATERIALS AND METHODS

3.1. Study description

In this project, the caregivers whose infants born at less than 37 weeks of gestation have been approached once they are ready to be discharged and stable for the transition to home. Based on the hospital guidelines (or usual practice), patients are discharged from the neonatology units once they can tolerate full feeds (above 160 ml/kg/day), feed independently, have a weight of at least 1650, and have reached 34 weeks gestation and above.

After a clear explanation about the purpose of this study and once we have received consent to participate in the study, we enrolled the main caregiver of the infant in the study. Socio-demographic data, obstetric and neonatal data were collected before discharge (from two sources: a "pre-discharge questionnaire" filled in by the main caregiver and the neonatal database being used in the Neonatology unit). The main caregiver provided at least 3 phone contacts through which to reach them during the week after discharge. Between one to three weeks post-discharge, the principal investigator called the main caregiver, reminded them about the study and asked if they had time for a post-discharge interview using a structured questionnaire in Kinyarwanda. The main caregiver was asked questions about the care of the premature infant at home including feeding, iron and vitamin D supplementation continuation, immunization, any episode of readmission at the nearest hospital, follow-up continuity to the nearest hospital, weight gain and KMC continuation. The discussion was recorded by a call recorder application to ensure that the conversation flowed efficiently and that the answers recorded on the data collection sheet were the ones provided by the parents. The principal investigator attempted to reach the parents with a least 3 attempts per day for 3 days within 2 weeks of the initial attempt. If despite these attempts, the investigator failed to reach the caregiver, the study participant was classified as failure to be reached.

The quantitative data were gathered into excel software then transferred to SSPS software for analysis, while some of the provided advice and possible open-end questions on preterm infants were grouped as qualitative themes in a single table.

3.2. Study design

Prospective descriptive study

3.3. Study site

The study was conducted in two teaching hospitals: First, in the University teaching hospital of Kigali (CHUK), a referral and teaching hospital with various departments which receives all patients from the northern, south eastern, all Kigali's district hospitals and western parts of the country. CHUK's neonatology department is equipped with 11 incubators, 7 radiant warmers, 9 cribs and a block with four beds for KMC where the preterm infants spend some weeks before being stable for discharge home. The Neonatology unit is also equipped to provide non-invasive respiratory support with 5 CPAP machines, nasal oxygen. For an average total 30 hospitalized newborns, there are on aver 4 nurses allocated in during the day and 3 on the night shift who work hand in hands with at least 2 residents under supervision of a neonatologist and/or a pediatrician. There are on average 650 patients per year hospitalized in the Neonatology Department with different conditions.

Because of time-constraint to enroll sufficient patients during the period of data collection, the study site was also enlarged to include patients from the Rwanda military hospital (RMH), a military based hospital and referral and teaching hospital in Kigali. RMH receives many patients from the eastern province and some from Kigali districts 'hospitals. The neonatology department has a neonatology intensive care unit with 4 neonatal ventilators machine and can also provide non-invasive respiratory support through 4 CPAP machines and oxygen therapy. RMH's neonatology department made of 10 incubators, 4 radiant warmers, 10 cribs and a KMC unit with 6 beds. The infants are usually discharged when their weight reaches at least 1650 gr. Some may be transferred for the continuity of care at the nearest district hospitals.

3.4. Study population:

Primary caregivers (mother (or/and father) whose preterm infants were admitted in neonatology departments at University teaching hospitals of Kigali or Rwanda military hospital (RMH and CHUK), from mid-September 2019 up to the mid-March 2020 and were ready to be discharged home

3.4.1. Inclusion criteria

Caregivers (mother, father or close caregiver) whose infant was born at less than 37 weeks of gestational age based on LMP or estimated Ballard score at birth and who were ready to be discharged home.

3.4.2. Exclusion criteria

Caregivers (mothers or fathers) whose infants were born with congenital abnormalities or whose preterm infants had HIE grade 2 or 3 as these are diagnosis which can significantly impact the level of care needed at home and the follow-up of the patients.

3.5. Sampling

A consecutive sampling methodology of all patients meeting the inclusion criteria during the study period of 6 months was used.

3.6. Procedures at enrolment

This prospective short period based longitudinal follow up was done in both neonatology departments of university teaching hospital of Kigali (CHUK) and Rwanda military hospital (RMH). Two data collectors completed the predischarge form including the principal investigator at CHUK and a hired trained neonatal nurse at RMH site, who was trained to explain the purpose of the study, ask for consent and to complete the predischarge forms of the questionnaire.

Prior to discharge, the data collectors explained the purpose of the study to the caregiver and, after obtaining consent from the caregivers whose infants met the inclusion criteria, enrolled the caregiver in the study. The data collector also completed with the participant a social demographic form and recorded also on this predischarge form with at least 3 alternative phone numbers, which were used to reach the caregivers. In addition, the clinical course information for that preterm infant was taken from the neonatology database; a database of clinical information that is collected for all patients admitted to the neonatology units. After filling the predischarge

data all questionnaires from RMH were handed over to the PI who used this form to contact the main caregiver of the preterm infant one to three weeks in post-discharge period. After piloting the questionnaire on 10 caretakers and making necessary adjustments and changes, the pre coded questionnaire was translated in Kinyarwanda prior to the beginning of data collection for easing the communication with the caretakers. Every data collection sheet was coded for computer entry.

3.7. Data management and analysis

Pre-discharge and post-discharge data were collected and then entered into EXCEL software for database creation, then exported to SPSS version 25 for analysis. Descriptive data were presented as follows: Categorical data were presented using frequencies and percentages in tables and charts. Continuous data were summarized by mean values and their standard deviations when normally distributed and by median values and interquartile ranges when skewed (not normally distributed).

Chi-square test and logistic regression were used to study the relationships between the outcomes and their possible predictors. Statistical significance for associations was taken at the level $p < 0.05$.

3.8. Measurements of variables (Exposures and confounders)

The following exposures and potential confounders were measured by the use of a data collection sheet:

- The gestational age (GA) (which is s always documented in the neonatology unit, once the mothers knew their LMP, the GA was estimated based on EED while if there was a discrepancy between the EDD and Ballard score or the mother /caretaker was not aware of the LMP, the admitting team considered Ballard Score, preterm infants were classified in the following groups according to their assigned gestational age (GA) at birth:
  - Late preterm infants – GA between 34 weeks and <37 weeks
  - Moderate preterm – GA between 32 weeks and <34 weeks
  - Very preterm (VPT) infants – GA at or below 32 weeks
  - Extremely preterm (EPT) – GA less than 28 weeks
- Weight on discharge
- Level of education of the main caregiver

- Main caregiver type (mother, father, grandparent, other)
- Maternal education on discharge
- Recommended medications prior to discharge
- Length of stay in neonatal unit
- Socio-economic level as measured by reported Ubudehe category
- Geography (province of origin, Distance to the recommended follow-up facility)
- Gender of the baby
- Medical insurance type

3.9. Measurement of Outcomes:

The following outcomes were measured:

1) Post-discharge survival of preterm infants at the time of the phone call.
2) Reported follow-up in recommended health facility (regular follow-up and ROP follow-up)
3) Reported follow-up by CHW within 7 days of arrival to home
4) Reported re-admission and reasons for readmission
5) Challenges encountered by mother or main caregiver such as
- Lack of mean to afford some medications prescribed on discharge
- Difficulties in feeding by bottle or breastfeeding
- Failure to keep follow-up in OPD and reported reason, including distance from health facility
- Presence of danger signs (Fever, diarrhea, vomiting, poor feeding, yellowish eyes, fast or difficult to breath, jerking movement, reduced activity level)
6) Reported adherence to KMC recommendations
7) Reported method of feeding
8) Reported adherence to medications
9) Success in reaching main caregiver by phone
10) Perceived usefulness of phone call by caregiver
11) Feasibility as measured by:
- Quality of call in terms of network and audible communication between the main investigator and caregiver

- Number of attempts to reach caregiver
- Number of those who were able to be contacted and provide the information regarding their preterm infants status in outpatients' transition period.
- Duration of call
- Advise provided and concerns addressed.

3.10. Sample size

This is a descriptive study, which doesn't require a sample size calculation. Consecutive sampling was followed in an attempt to enroll all eligible participants. However, to ensure that the sample enrolled was representative of the population of preterm infants discharged initially from the neonatal units at CHUK (University teaching hospital of Kigali, but after 1 month we were worried about not meeting the estimated sample size on time, to mitigate this we recruited RMH (Rwanda military hospital), the Sloven's formula was used for sample size calculation (31). For this, and basing our assumption on hospital registries for the last year, we anticipated and considered that there would be approximately at least 15 preterm infants discharged every month per every study sites; given that we aimed to complete the study in a 6 month period (so that the findings are not affected by systemic changes in the CHUK and RMH's neonatology unit and for convenience reasons), we estimated a total of 150 preterm infants discharged in a 6-months period in both sites.

$$n = \frac{N}{1 + N(e)^2}$$

Where N= Population size (here, 150 preterm infants), e: desired level of precision (or margin of Error= ±5%) (0.05). And n is sample size to be calculated. Our sample size calculation therefore allowed us to calculate a sample size of 109 preterm newborns.

3.11. Ethical considerations

Funding & Sponsors

No funding was sought for this project. The PI used his personal funds to finance this project.

Potential conflict of interest

The PI is a post-graduate in Pediatrics and this thesis is part of the requirements for graduation. One of the supervisors is the neonatologist in charge of the neonatal unit at CHUK. No other potential conflict of interest was identified.

Confidentiality

The main investigator kept the hard copies of information gathered during discharge period confidentially and in a locked cupboard. The data that includes personal identifier were kept separately than the de-identified data, which will include only a study ID. All recordings were transferred to a password-protected computer with password.

Informed consent

The mother (or main caregivers, in cases where the mothers had died) whose preterm infants were ready to be discharged from CHUK or RMH neonatology departments were given a verbal and written explanation of the purpose of the study and reassured that participation or not in the study would not influence the care they received. They were ensured that they had the right to leave the study at anytime without any consequences and were only enrolled after providing their written consent.

Incentives for subjects

There were no financial benefits to the caregivers or the infants for participating in the study. However, participating in this study allowed the caregivers to continue to access advice from a pediatric post-graduate about their preterm infants.

Risk to subjects

Physical risks:

No physical risks were identified

Social risks:

Time spent on the phone could be preventing the caregiver to attend to other important activities. We have asked the caregiver before going through the phone-based questionnaire if she or he was available to talk. If the main caregiver was busy she/he provided the suitable time that we could call again or denied to participate in post discharge phone call based interview.

Emotional risks:

Being asked about challenges could cause emotional distress for the caregivers. To mitigate this risk, before going deeper, the principal investigator made sure to conduct the phone interview in a sensitive manner using empathy and his skills and experience in counseling.

Legal risks:

No legal risk was anticipated. During the study explanation and before enrolling the patients, the role of the principal investigator (a doctor who is in the process of finishing his pediatrics and child health specialization, but would be providing advice on the phone without direct supervision) was clearly outlined.

Financial risks:

No financial support was obtained for this project. Some family may need financial support for medications, tickets for follow up consultations, which are part of routine care of preterm infants and were not incur an additional cost to the families. The fact that there was no financial incentive or benefits for the families participating in the study was highlighted during the participant enrolment.

Risk to researchers

There were no physical risks identified. However, there was the risk that the caregivers of the infant that he was not clinically responsible for while in neonatology was requesting medical advice that was beyond what a pediatric post-graduate can provide or contacting them beyond the context of the study. The principal investigator outlined his role and responsibilities in the consent form and adhere to established principles of professionalism when interacting with these families.

Ethical approval

This is study is the result of the proposal which was submitted to the University of Rwanda Institutional Review Board (IRB) IRB Ref: CMHS/IRB/403/2019 and the Research Ethics Committee (REC) of university teaching hospital Kigali/ CHUK (Ref: EC/CHUK/174/2019) and Rwanda military hospital /RMH (Ref RMH IRB/071/2019) for review and approval.

CHAPTER IV: RESULTS

A total of 472 patients were discharged during our study period, including 241 from CHUK (over 6 months between mid-September 2019 and mid-March 2020) and 231 from RMH (in four months, between mid-November 2019 to mid-March 2020). Out of these 472 patients, 319 were excluded, and majority of them were term babies and preterm with HIE, 153 were eligible for this study with 87 (57%) preterm infants from CHUK and 66 (43%) preterm infants from RMH. 43 of these patients were excluded and 110 were enrolled. Out of these patients, 86 were reached by phone and able to complete the telephone follow up interview.

Figure 1: Participant flow
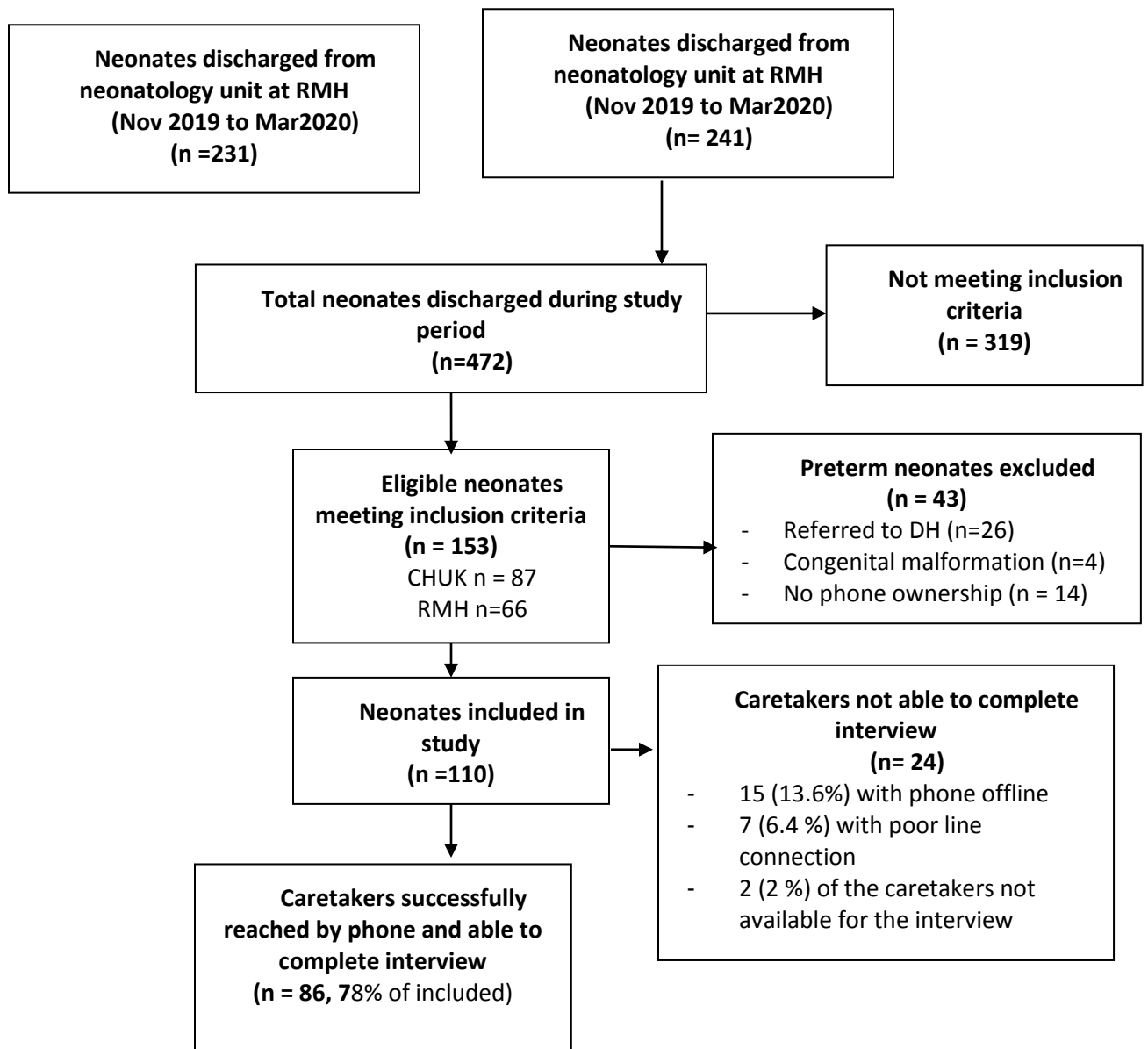
4.1. Characteristics of the participants

Approximately (55.45%) of the neonates were males, and (50.9%) were moderate preterm born at 32-34 weeks of GA. Their birth weights had a median of 1450 (1137-1700) grams while on discharge the infants 's weight had a median of 1879 grams (<1650 -2600) grams. The clinical characteristics of the newborns are detailed below in Table 1.

Table 1: Baseline clinical characteristics of newborns enrolled in study participants (n=110) and of patients successfully reached by phone interview (n=110)

Variables	N (110)	%
Sex of the neonates		
Male	61	55.45
Female	49	44.54
Gestational age at admission [Median (IQR	**32 (29-33) weeks**	
Category		
<28 weeks	10	9.1
28≤32 weeks	40	36.4
32≤34 weeks	56	50.9
34-37 weeks	4	3.6
Gestational age at discharge [Median (IQR)]	**35 (35-37) weeks**	
Category		
≤34 weeks	19	17.3
34-36 weeks	62	56.4
≥37 weeks	29	26.4
Birth weight [Median (IQR)]	**1450 (1137-1700) grams**	
Category		
<1000 g	14	12.7
1000-1499 g	45	40.9
1500-2499 g	49	44.5
≥2500 g	2	1.8
Weight at discharge [Median (IQR)]	**1825 (1750-2000) grams**	
Category		
<1650 grs	2	1.8
1650-2499 grs	106	96.4
>2500 grs	2	1.8

The majority of the participants were the mothers, and they came from all provinces of the country. The participant's socio-economic and educational characteristics are detailed in Table 2.

Table 1: Socio-economic characteristics of the study participants (n=110)

Table 2: Socio-economic characteristics of the study participants (n=110)

	n (110)		%
Primary caretaker of the enrolled newborn			
Mother	106		96.4
Father	3		2.7
Relative	1		0.9
Age of the mother [Median ((IQR)	**29 (25.0 -31.2) years**		
18-35 years	98		89.1
>35 years	12		10.9
Marital status			
Married	96		87.3
Single	14		12.7
Maternal condition during pregnancy			
Preeclampsia		33	30
Bleeding on pregnancy		30	27.3
Premature ROM/infection	36		32.7
Others ([1])	15		13.6
Education background of the primary caretaker			
No schooling /did not complete primary school	12		10.9
Completed primary school	40		36.4
Completed secondary school	37		33.6
Completed university	21		19.1
Province of origin			
Kigali	37		33.6
Eastern	30		27.3
Southern	23		20.9
Northern	13		11.8
Western	7		6.4
Economic status (Ubudehe)			
Category I	19		17.3
Category II	32		29.1
Category III	59		53.6
Category VI	0		0
Insurance Scheme			
Mutuelle de santé /CBHI	79		71.8
MMI	20		18.2
RSSB	9		8.2
Private	2		1.8

[1] Some mothers were having more than one reason for preterm labor. Other conditions include cervical incompetence, cardiomyopathy on pregnancy, and absence of fetal movements.

4.2. Medication and modalities of nutrition on discharge

On discharge, the majority (83.6%) of patients were prescribed iron, 80.9 % a combination multivitamin suspensions while 79.1% of were prescribed vitamin D on discharge (Table 3).

Table 3: Prescribed medications on discharge

Variables	N (110)	%
Medications prescribed		
Iron supplements	92	83.6
Multivitamin [1]	89	80.9
Vitamin D	87	79.1
Others[2]	5	4.5
No supplements prescribed	16	14.5
Nutrition on discharge		
Breast milk exclusively	80	72.73
Combination of breast milk and Formula milk	24	21.82
Formula milk exclusively	6	5.45

[1] Multivitamins supplements,

- Every 5 ml of Multivitamin contain the following vitamins A (1500 IU), B1 (0.5mg), B2 (0.5mg), B3 (Nicotimade=5mg), C (20mg), and D: 25IU.

- [2] Others medications include: syrups of Hydrochlorothiazide, furosemide, Trimethoprim/sulfamethoxazole or antiretroviral therapy.

4.3. Feasibility and usefulness of post-discharge phone calls

Out of the 110 participants included in the study, 86 (78.2%) were successfully reached by phone within one to three weeks after discharge. The majority 72 (84%) was successfully reached within 1st -2nd week after discharge while 14 (16%) were reached between 2nd -3rd weeks post discharge. 24 (21.8 %) of the participants were not able to complete the questions despite 8 or 9

attempts within in 3 days of the first attempt. Of these, 15 (13.6%) caretakers' phone were offline, 7 (6.4 %) had a poor quality connection which prevented a full interview from being successfully conducted and 2 (2 %) of the them never picked up their phones. The median of phone calls duration was 840 (774-900) sec=14 (12-15) minutes.

The details of the feedback is presented below in Table 4

Table 2: Phone call implementation details and feedback received about phone call

Variable	n (86)	%
Phone Call duration [Median (IQR)] in seconds= minutes	840 (774-900) sec=14 (12-15) minutes	
Number of call attempts [Median (IQR]	3 (4-2) times	
Day of successful call after discharge		
1-2weeks	72	83.7
2-3 weeks	14	16.3
Feedback for the call		
Was this phone call useful?		
Yes	84	97.7
N/A [1]	2	2.3
Have you been able to hear me clearly?		
Yes	82	95.35
N/A [1]	2	2.32
No	2	2.32
Do you think all parents of premature babies discharged from CHUK should receive a phone call like this?		
Yes	84	97.7
N/A [1]	2	2.3

N/A[1]: Not applicable to the caretakers whose preterm infants passed away after getting home for transition care

[2]others means that the caretakers were either not available or the phone were disconnected

4.4. Challenges reported and advice provided

During post-discharge phone calls, the participants answered the PI's closed-end questions, however, some of the caretakers expressed either their challenges or asked the advice for care the

preterm infants, these kinds of pertinent open-end questions were grouped in themes. See the summary in the following Table 4.5.

Table 4 3: summary of question asked and challenges reported

		Advice from PI and supervisor
Challenges reported	Supplements expensive and not covered by CBHI	The study is the preliminary check-up and we would like to have a local image on post-discharge care, so we will be advocating whenever it is possible.
	New symptoms and not sure what to do (abdominal pain and discomfort)	Caretakers (mothers) were advised to change her diet schedule through the increase of fibers based diet, water consumption, or change the infant formula type, and consult the pediatricians if no change
Questions answered	Recommended duration of supplements	Normally the literature and the Rwanda neonatology protocol recommend at least 6 months for Vitamin D supplements and 12 months for iron supplements
	When to start vaccinations in preterm infants	The same vaccination schedule as the full term infants should be used in preterm infants, with the first dose being given at 7 days of life (based on the day of birth), the second dose at 6 weeks of life, etc. Your baby is already late with his immunization so it's very important that you go to the health center and have him vaccinated.
	Duration and frequency of breastfeeding	As long she/he ask or is willing to breastfeed keep nursing her/him, waking him/her for feeds, if needed, with a minimum frequency of least 8 times per day or even above.
	Introduction of complimentary feeding	Should be started at least 6 months from the expected day of delivery?
	Recommended duration of KMC, when to start back-carrying	KMC should be frequently continued until the infants reached at least 2 kg, back-carrying is discouraged in less than 2kg preterm infants. The mother should keep on good hygiene while doing both and avoid hypothermia

4.5. Home care and adherence to the post discharge recommendations

According to the a scale from 1 to 10, where 10 was extremely difficult and 1 stood for very easy, the caretakers answered how hard it was to care for the preterm infants with a median of 5 (IQR: 3-7.75). The (57) 66.3% of the reached participants were exclusive breastfeeding, most of them (81.4 %) reported to be ready for continuation to the preterm infants care, the majority (86%) of them continued KMC at home, and 83.7% of them continued the supplementations mainly iron and vitamin D variants, details are in Table 5 below.

Table 4: Reported home care at home and adherence to the post discharge recommendations

Variable	n=86	%
Feeding practice at home by the caretakers (n=86)		
Exclusive breastfeeding	57	66.3
Combined formula milk and breastfeeding	25	29
Cow's milk/formula	3	3.5
Cow's milk	1	1.2
Frequency of feeding per day [Median (IQR)]/day	**12 (8-12) times**	
Reported feeling ready on discharge to care for the baby at home		
Yes	70	81.4
No	16	18.6
Reason of not being ready [1]		
Fatigue	12	75
Financial issues	8	50
No equipment	6	37.5
Busy with other children/working	2	12.5
No breast milk	2	12.5
Other reasons	8	50

Difficulty scale of caring for preterm infant (category n=84) [2]		
(1- 3)	40	47.6
(4 - 6)	23	27.4
(7 -10)	21	25
KMC continued at home		
Yes	74	86
No	12	14
Mean time of KMC per day [Median (IQR)]		3.5 (3.0-5.0) hours/day
Reasons of not doing KMC (n=12)		
Not needed (age and weight)	8	66.7
It is to hard/difficult	2	16.7
Other reasons [3]	2	16.7
Infant still taking supplementations		
Yes	72	83.7
Not recommended by physicians	13	15.1
Family can't afford to buy them	1	1.2
Types of supplements (n=72)		
Iron (out of 92 patients being prescribed iron)	69	95.8
Vitamin D (out of 87 patients being prescribed)	60	83.3
Others [4]	67	93

Index ([1]): note that some of the caretakers reported more than one reasons, the other reasons reported were: the first experience, fear, worries about their infants 'growth and fragility

Index ([2]): the Likert scale was applicable on the caretakers whose infants were still alive after while reaching them on call after discharge where the score was estimated at 1= very easy, 10 = extremely difficult)

Index ([3]): sick infants in the first days post discharge or hospitalized

Index (⁴) the parents reported to keep given other medication such as Antiretroviral therapy, multivitamins or Bactrim

4.6. Outcome, homes care and follow up of discharged neonates

Eighty-four (97.7%) of the participants reported their preterm infants to be still alive while, two (2.3 %) of the infants passed away during transitional home based care.

Many of caretakers (84.9 %) reported to see a pediatrician or a GP at nearest hospital for their infant's wellbeing. Only 55.8% of participants reported that their infants were vaccinated after discharge, only 48.7% of them were visited by the CHWs after discharge, and 38.4% of them reported their infants had been screened for ROP. (Table 6)

Table 5: Wellbeing follow up of the discharged neonates

Variables	n (86)	%
Reports being given appointment for follow up **before discharge**		
Yes	81	94.2
No	5	5.8
Visit by CHW in 7 days post discharge		
Yes	41	48.7
No	45	53.3
Consultation of GP or pediatrician after discharge at DH or PH /CHUK/RMH (n=86)		
Yes	73	84.9
No	13	15.1
Time of consultation after discharge		
7-14 days	46	63
≤7days	27	37
Readmissions to health facility since discharge	6	7
Reason for readmission (n=6) (¹)		
Apnoea or difficult of breathing	1	16.7
Fever	4	66.7

Poor feeding/weight gain	6	100
Less active /hypotonic	5	83.3
Others [2]	5	83.3
Started vaccinations (n=86)		
Yes	48	55.8
No	38	44.2
Reasons of not starting vaccination (n=38)		
The nurse refused to vaccinate [3]	33	86.8
Lack of awareness	3	3.5
Other reasons[4] (infant's sickness, transport etc.)	2	2.3
Weighed since discharge		
Yes	79	91.9
No	7	8.1
Reported weight gain (n=79) [4]		
Yes	78	98.7
No	1	1.3
Reported attending ROP screening follow up (n=86)		
Yes	33	38.4
No	53	61.6
Reasons of not screening for ROP (n=53)		
Not recommended by Pediatrician	24	45.3
Lack of means or transport/financial	12	22.6
Transfer issues (insurance, RDV)	14	26.4
Not recommended by any of the discharging team	3	5.7

Index [1] Note that some participants stated more than one reasons of readmission

Index :[2] others symptoms were: Hypothermia, Vomiting, jaundice, not passing urine or not passing stool excessive cry.

Index [3] Some of the caretakers reported sometimes nurse recommended us to wait until the infant reaches above 2kgrs or to wait until the infant reached the corrected GA of their due EED

Index [4]: parents who consult for their infants' routine follow up and weight check up at health center in their first 2 weeks after discharge

4.7. Bivariate analysis

Though studying the association between socio-demographic factors and follow up outcome was not an objective of this study, a chi-square test was done and revealed no statistical significance on the association of participant's level of education and follow up to KMC or vaccination practices of the preterm infants (Table 7)

Table 6: Association between the Level of education and continuity of care

Educational level	Yes	No	OR (95% CI)	P value
Started vaccination				
No schooling/did not complete primary school	5 (41.7%)	7 (58.3%)	Ref	
Completed primary school	7 (17.1%)	34 (82.9%)	0.3 (0.07-1.1)	0.083
Completed secondary school	24 (66.7%)	12 (33.3%)	2.8 (0.7-10.7)	0.132
Completed University	12 (57.1%)	9 (42.9%)	1.8 (0.4-7.8)	0.394
KMC continuity at home				
No schooling/did not complete primary school	8 (66.7%)	4 (33.3%)	Ref	
Completed primary school	21 (51.2%)	20 (48.8%)	0.5 (0.1-2.0)	0.348
Completed secondary school	29 (80.6%)	7 (19.4%)	2.0 (0.5-8.8)	0.327
Completed University	16 (76.2%)	5 (23.8%)	1.6 (0.3-7.6)	0.556

Table 4 7: Association of patient's follow up and their area of residence

Variable	Residence		OR (95% CI)	P value
	Kigali	**Out of Kigali**		
Pediatrician follow up				
Yes	23 (71.9%)	20 (37.0%)	4.3 (1.68-11.2)	0.002
No	9 (28.1%)	34 (63.0%)		
ROP screening				
Yes	13 (39.4%)	20 (37.0%)	1.1 (0.45-2.69)	0.826
No	20 (60.6%)	34 (63.0%)		

Caretakers in Kigali were 4.3 times to follow pediatrician follow up visits compared to caretakers who were outside Kigali city and the difference was statistically significant (OR: 4.3; 95%CI: 1.7-11.2; p=0.002).

Caretakers from Kigali city were 1.1 times more likely to report having followed up for ROP screening compared to caretakers living outside Kigali (OR=1.1, 95% CI 0.4-2.7, p=0.826), although this was not statistically significant.

CHAPTER V: DISCUSSION

V.1. Feasibility of phone calls follow up on the preterm infants during transitional care

Our study was conducted in two referral hospitals of a resource limited country, where the majority of preterm infants were discharge after reaching weights above 1650g and all were above 34 weeks gestation, able to feed without a nasogastric tube, and maintain stable breathing pattern on room air. These preterm infants meet the discharge criteria of the Rwanda National Guidelines. This is in contrast to a recent study done in the region, in Mulago hospital, Uganda, where there was a where there is a high mortality of 81.7% in the early discharge period in infants who are discharged while they were still using a nasogastric tube for feeding, were under 35 weeks gestational age or less than 1200gm(9,32). The condition of the preterm infants in our study was therefore optimal and should lead to the best outcome possible.

To better understand the transition to home of these preterm infants, we used a post-discharge telephone call and were able to successfully reach 86 (78%) of the preterm infants discharged during the study period. The success in reaching parents by phone was much higher than another study carried out in Malawi, were only 29.5% of the parents of acutely ill children less than five years discharge from a local clinic were reached (26).

All caretakers of alive infants reported that the phone call was helpful and recommended this should be done for all preterm infants. During these phone calls, the investigators were able to answer questions and solve some challenges encountered by parents caring for these preterm infants. Although assessing the effectiveness of the phone calls in resolving these challenges was not the objective of this study, implementing these phone calls is a solution that could supplement other interventions such as the one done in a rural area in Malawi, where a skilled medical profession goes to the community to provide education on preterm infants home based care and can alleviate some barriers to quality care (33). In previous studies done both in limited resources or high income countries, the interventional support either by home visit or phone-based during transitional care can help the caretakers to cope with the survival worries and stress after the discharge of the preterm infants and can also decrease the rate of readmissions (22,27,34,35). However, exploring the effectiveness of the phone calls delivery care to improve the preterm infants outcome was beyond the scope of our project but a study could be undertaken in the future

V.2. Participants KMC and breastfeeding practice at home

The role of this type of telehealth follow up by phone has been shown in many studies in higher income settings to decrease critical clinical related issues such as medication prescriptions errors or misunderstandings with discharging team on discharge instructions which often happened in the first 72 hours after discharge (36). Studies have been done in high income countries to improve the outcome of patients with chronic diseases, and the phone-based follow up on has been associated with reduced preventable readmissions, and adherence to the post-discharge recommendations (12,37). Our study is the only study done in sub-Saharan Africa where post-discharge phone calls were used to follow up on preterm infants. Of 86 who were reached on phone calls, 86% of participants reported keeping their infants on KMC, but only for a few hours per day. When performed correctly, KMC has been shown in many studies both in countries with limited resources or high income to be linked with improved growth, low mortality rate and decreased rates of infections. KMC is therefore recommended at least until the infants reached 2000grs (38,39), In our study, most (90%) reported their infant had gained weight, however, the median of duration per day was only 3.5 (3.0-5.0) hours, which was not appropriate and may place these infants at risk of readmissions, hypothermia, poor weight gain, and poor feeding, etc. In Kenya, for example, a study found that KMC is effective once the duration is at least 8 hours per day (40).

However, there is still a paucity of its continuity of KMC in the post-discharge period (41). Poor adherence to KMC has also been found in a study done in a rural area in the southern province in Rwanda, where a retrospective study found that KMC was perceived as hospital-based practice, explaining the discrepancy between the in-hospital the community-based practice(42). In order to better understand why caretakers are reporting performing KMC only for a few hours a day, and whether this is due to fatigue, lack of equipment, being busy with other children or household responsibilities or other reasons.. Further studies are needed to explore the practice or perception of community-based of KMC and its impacts on the preterm infants in transitional care

Prior to discharge most of the caretakers (mothers) were encouraged to breastfeed since it's affordable and linked with low mortality and morbidity(43). However, in the reached participants, only 66.3% of infants after one or three weeks post-discharged were still on exclusive breastfeeding of the while 29% kept on combination of breast milk and infant formula.

We also found that although cow milk is discouraged, 4.5% were either feeding the infants with cow milk or combined formula milk and cow milk. This is concerning as these preterm infants are often already malnourished and at high risk of malnutrition. The discharge infants weight were not checked in this study, and despite the high percentage of caregivers reporting weight gain, further studies should be undertaken to better understand and address the reasons behind this low breastfeeding rate.

V. 3. Vaccination, CHWs visit, follow up at nearest DHs and ROP screening

Since most of the mothers in limited resources countries are exclusively feeding their infants by breast milk, supplementing their infants with vitamin D and iron to prevent iron deficiency anemia or osteopenia of prematurity is recommended (17,44,45), Our study reveals that only 83.7% of the caretakers reached by phone reported that they were supplementing their infants mainly with iron and vitamin D variants, while 16.3 % of them weren't taking them, with the majority reporting that they didn't receive any recommendation from the discharging physician. This study revealed an area that can be improved during the discharge education but further studies are still needed to assess the longer-term adherence to them.

Our study revealed that follow up of these preterm infants is inadequate. For better transition care, the discharging team recommended the caretakers the follow up of their infants at either the nearest DH or referral hospital after 1 week of discharge. Although either a GP or a pediatrician reviewed 84.9% of the caregivers reached by phone, our study didn't go beyond the three weeks and scrutinize if there is a type of a long time follow up on the preterm infants. In low resource setting countries, little is known about an organized program of tracking the preterm infants' growth and development surveillance. The study done in Rwanda in the rural eastern region showed that the preterm infants were experiencing feeding difficulties at 46.5% and poor growth at 8.8%(24). In Kenya a short longitudinal study showed there is link with post-discharge growth deficit and gestational age (46). Not only was the follow up for weight monitoring insufficient, we also found that there was poor follow up for vaccination. Preterm infants should be vaccinated based on the same chronological schedule of the term infants and same doses with the exception of Hepatitis B vaccines (47–49). Vaccines are not given to preterm infants who are still in the neonatology units at CHUK or RMH and among the caregivers reached by phone only 55.8% of their infants were vaccinated, with most reporting that the reason their infant didn't receive vaccines is that the vaccination clinic nurses delayed their vaccination. This is

particularly concerning as it may lead to early illness and severe sepsis that can be prevented through vaccination. Similar findings were reported in the mixed study done in Uganda where ELBW or very preterm (with a P~0.001) or extreme preterm (with P~0.002) was linked with delayed of vaccination, fear of its side effects, or inadequate knowledge of the vaccines providers(35), in Rwanda studies and training of the health care providers are needed for further understanding the vaccination approach in preterm infants. In addition to follow up for vaccination, the national guidelines in Rwanda recommend that community health's workers (CHWs), who are the pillars of the health care system at the community level and can facilitate and strengthen the transitional care and their subsequent follow up especially to these infants at risk (43) should visit the preterm infants within seven days of discharge. In our study, only 48.7% of the participants reported to be visited by the CHWs while 51.3% of them didn't receive any visit of the CHW. This is another area of follow up which is concerning and should be improved

In our study majority (61.6 %) of the caretakers reported that their infants weren't screened for ROP due to either lack of transport means or delayed transfer process. The Rwanda Neonatal guidelines are clear and recommend that preterm infants at risk of ROP should be screened early based on their gestational age or days spent on oxygen before leaving the neonatology unit department. All infants born at less than 32 weeks of GA should be screened within 31-36 weeks of postmenstrual age(50), for early detection of ROP and a follow up should be done for those at risk. However, our study result suggest that there a clear consensus is needed between neonatologist or pediatricians and ophthalmologist and that, in addition to clear explanations about the need for follow up, a system should be put in place to facilitate this.

Many parents in our study still reported not feeling ready at the time of discharge to be able to take care of their infants and report finding it difficult to care for their infants. Though this was not in our objectives and our sample size was not powered to detect these associations, we found that higher socio-economic status was linked with readiness of the caretakers to home-based care for the preterm, with parents from higher socio-economic strata, reporting being 3.6 times more likely to report feeling ready to continue care at home compared to caretakers in the low socio-economic status (OR 3.6; 95%CI: 1.2-11.2; p=0.025). We also found that living far away from the referral hospital was linked poor follow up on ROP (OR: 4.3; 95%CI: 1.7-11.2; p=0.002) or pediatrician review (OR: 4.3; 95%CI: 1.7-11.2; p=0.002). This can be compared to the study

conducted in Iran, the mother in showed that there is no statistical significance on the correlation between low economic status and the preterm infants' post-discharge follow up, however high level of education was strongly associated with maternal attendance to the preterm infants 'wellbeing clinic comparatively to the one with the low level of education(14).

V.3. Study limitations

This study was only covering the mothers whose infants were discharged from two teaching hospitals based in Kigali, which may not be representative of all hospitals in Rwanda, as the means to care for the preterm infants and systematic education for inpatient caretakers may be different

The study was using a descriptive approach but was not powered to detect differences in groups. For this, a larger sample size or a matched group controlled study would be needed to be able to detect differences among groups

The reported "Yes "/ "No" on closed ended interview based questions can strongly generate bias since the parents /caretakers have little knowledge on the preterm infants transitional care practices compared to any trained health care provider. In order to fully explore these issues, further studies, including qualitative studies should be conducted

In this study, we used the gestational age (GA) documented in the file, which is based either the new Ballard score or based on the reported EDD. The GA may therefore not have been as accurately estimated as if it had been based on a first trimester ultrasound.

The outcome of preterm infants in the early post discharge period was only assessed by parents 'report (i.e. there was no actual measurement of preterm infants' outcomes). Some interventions may need physical assessment by the physicians and this phone call based may be biased by the fact that the mothers/caretakers may not be familiar with alarming signs and pathological behaviors of their preterm infants and that not being able to reach a certain population of discharge preterm infants could be in itself a selection bias.

Some caregivers might have been missed from follow-up during the study period and these parents might be facing different type of challenges than the ones who were reached.

CHAPTER VI: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

Although little was known about the post-discharge follow up of preterm infants in Rwanda prior to this study, this study contributed to a better understanding of the transition to home of preterm discharged from tertiary hospital in Rwanda. Home management and follow up with CHW, for vaccination and for growth and development monitoring of these preterm infants is still suboptimal and care of the preterm infants is difficult for most parents and interventions should be developed and implemented to improve the discharge process and at home transition.
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6.2. Recommendations

To the healthcare providers and discharging hospitals

- Education on the preterm infants' vaccination approach is needed since no harmonized way of their schedules to avoid the nurses' reluctance to the vaccination.
- The discharging teams in neonatology units are encouraged to emphasize on both pre and post discharge KMC utilities, technics, and recommended duration per day either in hospital and at home once the preterm infants still have less than 2500grs on discharge.
- The neonatology's units could make regular systematic schedules for ophthalmology consults and ROP screening, because some may be lost or miss the transport means for OPD based follow up.

To the ministry of health

- A specific OPD's clinic with a structured and systematic (with a focal point nurse and GP if no pediatrician allocated at DH) for long term follow up for the preterm infants is needed at the level of every district hospital is needed
- A regular mentorship and training for the primary health providers (i.e. nurses at health centres or health posts and CHWS) on premature infant vaccination practices, and continuation of care at home.
- To encourage the districts hospitals to avail the supplements medication (irons and Vitamin D variants) in their pharmacies, since many of the caretakers use community-based insurance

To the future researchers

- Further intervention studies using phone delivery care especially RCT are needed since our country have high phone penetration rate.

- Local multicenter studies to explore the care of premature infants and survival after being discharge from neonatology's units at DHs, referral hospital or teaching hospitals   are needed

- The future long term follow up studies exploring some practices such as ROP screening, neurodevelopmental follow up or hearing loss linked with prematurity, and the adherence to supplements especially to iron and Vitamin D varieties are needed as well.

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APPENDICES

Appendice 1. Literature Search terms (MeSH)

Pub Med Search terms (MeSH)	Results
"infant, extremely premature"[mesh]) or "infant, premature"[mesh]) or "infant"[mesh]) or "infant, low birth weight"[mesh]) or "infant, very low birth weight"[mesh]) and "cell phone"[mesh]) or "telephone"[mesh]) or "health transition"[mesh]) and "infant care"[mesh]) or "kangaroo-mother care method"[mesh]	322 abstracts found 5 matching full articles pulled See the literature search table
cochrane library and google scholar "phone call " or telephone and follow up or home care or feasibility of phone call follow up. ((((((("Continuity of patient care"[mesh]) or "transitional care"[mesh]) and "infant, premature"[mesh]) or "infant, extremely premature"[mesh]) and "caregivers"[mesh]) or "health personnel"[mesh]) or "community health workers"[mesh]	1250 articles pulled 45 matching full articles pulled
scientific research an academic publisher (scrip.org), mendeley alert message « preemies post discharge care », « follow up of preemies »	112 articles pulled 12 matching full articles considered
African journals online "phone calls follow up " Post discharge KMC.	8 articles but only 3 were based on pediatrics fields. On KMC, 3 were pooled

	("Infant, Premature"[Mesh]) OR "Infant, Newborn"[Mesh]) OR "Infant, Very Low Birth Weight"[Mesh]) OR "Infant, Low Birth Weight"[Mesh]) OR "Infant, Extremely Low Birth Weight"[Mesh]) OR "Transitional Care"[Mesh]) AND "Outpatient Clinics, Hospital"[Mesh]) OR "Ambulatory Care Facilities"[Mesh])
AND	(*"Cell Phone"[Mesh]) OR "Telephone"[Mesh])*
AND	(*"Continuity of Patient Care"[Mesh]) OR "Aftercare"[Mesh])*
AND	*(Developing Countries* OR developing country OR countries, developing OR nations, developing OR developing nations OR *Poverty* OR resource limited OR resource-limited OR resource poor country OR low income country OR low-income country OR resource-poor country OR *Global Health* OR third world OR India OR Africa OR Asia OR South America OR Papua New Guinea OR Asia-Pacific)
Search date:	29th /March - 2nd-September 2019

Appendice 2: Consent form (English)

REASSEARCH TITTLE: "Perspectives of caregivers on home transition of premature babies assessed with the use of a post-discharge telephone call in a Rwandan teaching hospitals (CHUK and RMH)."

Study ID:……………………………………

We want to know how to improve the transition from the hospital to home for premature babies. For this, we would like to invite you to participate in this study.

In this study, we will recruit all parents of premature babies who are discharge to home from the neonatology department at the University teaching hospital of Kigali and Rwanda military hospital's neonatology departments. The aim is to first obtain some information about the hospital course of your baby. For this, we will ask you a few questions about how to reach you and we will also get some information from the medical record of your baby.

We will then call you in 2-3 weeks after discharge and interview you on the phone and ask you questions about how you are able to care for your baby at home. The phone call will last from 15 to 30 minutes and Dr. MUBILIGI, a doctor who is finishing his training to be a pediatrician will be calling you. On this phone call, Dr. MUBILIGI may, if you wish, also answer your questions and provide you some advice that could potentially help you if you are facing some challenges taking care of your baby. Please know that he is not yet a Pediatrician or a neonatologist and will answer your questions to the best of his knowledge.

There will be no additional cost as a result of participation in this study and you are free to refuse to participate or, at any point, withdraw from the study without any consequences of the care given to your baby.

We will maintain high confidentiality on the data that is collected and no individual identifiers will be published or shared at any point. The information obtained you're your baby's medical files and from the phone call will be used for educational and research purposes only.

In case a clarification is needed, you should feel free at any point to call and contacts: Dr Alexandre MUBILIGI who is the principal researcher and will be the one calling you: +250 784076252. You may also reach out to Dr Natalie McCall (Pediatrician): +250788381561, Dr Agaba Faustine (Neonatologist) +25088438837 or Dr Aimable KANYAMUHUNGA (Pediatrician, Head of Department at CHUK) +250788670200

I, ---, have been fully informed about the purposes of the questions that I will be asked and my questions have been answered satisfactorily. I hereby, fully consent to participate in this study on the "Perspectives of caregivers on home transition of premature babies assessed with the use of a post-discharge telephone call in a Rwandan teaching hospital"

Name of the participant	Signature of the participant	Date
Name of the resident	Signature of the resident	Date

Appendice 3: Consent form (Kinyarwanda)

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI KUBUSHAKE BWITWA "Perspectives of caregivers on home transition of premature babies assessed with the use of a post-discharge telephone call in a Rwandan teaching hospitals (CHUK and RMH)."

Nimero yuri mu bushakashatsi: ……………………………
Muri ubu bushakashatsi turashaka kumenya uko twarushaho kwita kubana bavuka batagejeje igihe cyanecyane igihe bageze imuhira barasezere mu bitaro, niyo mpamvu ari ingiriakamaro kubwitabira.

Muri ubu bushakashatsi tuzifashisha ababyeyi bafite abana bavutse batagejeje igihe basezerewe mu bitaro bagiye imuhira, igice cyambere kigamije kumenya amakuru azashingirwaho mukubabaza amakuru kuri telifoni igihe bazaba bageze imuhira, mbere yo gutaha tuzifashisha amakuru y'ibanze tuzahabwa nababyeyi ndetse nayo tuzakura mu mafishe yo mubitaro.

Hifashishijwe telifoni tuzabahamagara nibura hagati y'icyumweru kimwe na bitatu ababyeyi cg abantu bahafi bita kumwana nibo tuzahamagara , hagamijwe kumenya uko kwita kumwana byakomejwe nyuma yo kuva mu bitaro, hifashishijwe ibibazo umubyeyi azasubiza mu minota iri hagati 15 kugeza kuri 30 Dr MUBILIGI ALEXANDRE umuganga uri mu mwaka wanyuma wihugura kuvura abana niwe uzabahamagara. Kuri telifoni muganga Mubiligi Alexandre ashobora kubaha inama cg ubufasha bugamije gukomeza kwita ku mwana wanyu. nta mafaranga azatangwa kumuntu winjiye muri ubu bushakashatsi, umubyeyi yemerewe kubyanga, kubyemera cg akava mubushashatsi abyemera igihe abishatse ntangaruka bizamugiraho.

Amakuru yose azaba yatanzwe azabikwa neza kuburyo bw'ibanga kandi turabizeza ko azakoreshwa muburyo bwo guhindura uko abana bavuka bagejeje igihe bakwitabwaho biruseho ndetse no mubundi bushakashatsi.

Ukeneye amakuru arenzeho wabaza muganga Alexandre MUBILIGI arinawe ukora ubushakashatsi numero ya telifoni yiwe ni: +250 784076252, wabaza kandi abaganga bakurikira

bakorana nawe byahafi DR NATALIE MCCALL: +250788381561; Dr Agaba Faustine: +25088438837, nukuriye ibitaro byabana muri CHUK Dr Aimable KANYAMUHUNGA: +250788670200, naho kubitaro bya gisirikare i Kanombe afatanyije na: Dr Nyirasafari Rosine Tel:+250788633418

Jyewe, …………………………………………………...nyuma yo gusobanurirwa neza ubushakashatsi bwitwa" **"Perspectives of caregivers on home transition of premature babies assessed with the use of a post-discharge telephone call in a Rwandan teaching hospital".** nemeye kujyamo.

Amazina y'uwemeye :	umukono w'uwemeye kujya mubushakashatsi	Itariki. /…/…
Izina ry'ukora ubushakashatsi cg Umuhagarariye :	umukono w' ukora ubushakashatsi cg Umuhagarariye :	Itariki. /…/…

Appendice 4: Pre and post discharge questionnaire form

SECTION 1: Patient identifiables

NAME OF PRIMARY CAREGIVER WHO WILL TAKE CARE OF BABY AT HOME (From whom consent taken and to be interviewed):

order	Parent/caregiver name	Phone number	Relationship to parent	Preferred day of call	Preferred time of call
1					

After the parent gives you his/her number, please call him

Test call made. [] YES- SUCCESSFUL -. Please still obtain contact information for at least 3 numbers for contacts   on whose phone you could still reach the main caregiver (below)

> **[] YES – UNSUCCESSUL -> Please try again**
>
> **[]   No   –   please   write   down   reasons: _____ and try again another time**

Other Caregivers/family numbers who have mobile telephone – potential contacts to identify and call the above primary caregiver

" We will call you to discuss how your experience is at home, can you please provide at least 3 numbers on which we can reach you? "

Order	Parent/caregiver name	Phone number	Relationship to parent	Preferred day of call	Preferred time of call

1				
2				
3				
4				
5				
6				
7				

Rwanda Neonatal Data Collection   Last update: 26Sep 2014

PATIENT	Name of baby: Hospital ID:
HISTORY	Sex: ☐ M ☐ F DOB: dd/mm/yy Time : GA: weeks ☐ Prematurity
	Birth place: ☐ Tertiary Hospital ☐ District ☐ HC ☐ Home ☐ Other
	Steroid completed: ☐ None ☐ 1 dose ☐ 2 doses ☐ 3 doses ☐ doses
	Type Birth: ☐ Vaginal ☐ Cesarean
	Co-existing complication: ☐ Eclampsia ☐ Pre-eclampsia ☐ Maternal fever
	☐ Other:
	☐ Congenital anomalies:

ADMISSION	Date: dd/mm/yy BW: g HC: cm L: cm Temp: °C
	APGAR (5 min): APGAR (10 min):
DISCHARGE	Date: dd/mm/yy Wt: g HC: cm L: cm

RESPIRATION	☐ RDS ☐ TTN ☐ Meconium aspiration syndrome ☐ Pneumonia ☐ PPHN
	☐ other:
	☐ CPAP, if yes: Date start : dd/mm/yy Time : Date Stop: dd/mm/yy
	☐ HF, if yes: Date start : dd/mm/yy Time : Date Stop: dd/mm/yy
	☐ Vent, if yes: Date start : dd/mm/yy Time : Date Stop: dd/mm/yy
	☐ O_2, if yes: Date start : dd/mm/yy Time : Date Stop: dd/mm/yy
	Complication: ☐ Pneumothorax ☐ BPD ☐ ROP ☐ Other:

CV	☐ PDA; if yes, Date: dd/mm/yy Diagnosed by: ☐ Echo ☐ Clinical
	Ibuprofen course 1 dates: Dose 1: dd/mm/yy Dose 2: dd/mm/yy Dose 3: dd/mm/yy
	course 2 dates: Dose 1: dd/mm/yy Dose 2: dd/mm/yy Dose 3: dd/mm/yy
	☐ PDA resolved; if yes, Date: dd/mm/yy Diagnosed by: ☐ Echo ☐ Clinical

FEN	☐ Hypoglycemia ☐ Hyperglycemia
	☐ Regained BW; if yes, Date: dd/mm/yy Mother poor breastmilk supply>7 DOL: ☐ Yes ☐ No
	Max fortification (kcal/ml): ☐ 0.66 ☐ 0.73 ☐ 0.8 ☐ other
	Max volume (ml/kg/day): ☐ 150-160 ☐ 161-190 ☐ >190

GI	☐ NEC, if yes, date: dd/mm/yy Diagnosed by: ☐ Clinical ☐ XR, if yes, stage: ☐ I ☐ II ☐ III

HEME	☐ Anemia (Hb≤10g/dl) ☐ Polycythemia
	☐ Transfused pRBC 1: dd/mm/yy 2: dd/mm/yy 3: dd/mm/yy Total #:
	☐ Jaundice, if yes, photo treatment begin: dd/mm/yy End: dd/mm/yy

RENAL	☐ Acute kidney injury ☐ Electrolyte imbalance

INFECTION	☐ Non-specific infection
	☐ Sepsis ≤ 3 days ☐ Sepsis > 3 days
	Diagnosed by: ☐ CRP ☐ Blood culture, if yes, bacteria sp:
	☐ Neonatal meningitis
	Diagnosed by: ☐ CSF cell count ☐ CSF culture, if yes, bacteria sp:
	☐ Resistant to Amp ☐ Resistant to Gent ☐ Resistant to Cefotax

IATROGENIC INJURY	☐ Tourniquet injury ☐ IV extravasation ☐ Nasal trauma ☐ Other:

NEURO	☐ HIE, if yes, grade: ☐ I ☐ II ☐ III ☐ Normal exam at DOL 7
	☐ IVH, if yes, grade: ☐ I ☐ II ☐ III ☐ IV ☐ Kangaroo care started, if yes, date: dd/mm/yy

OTHER REMARKS	

DEATH	☐ Death, if yes, date: dd/mm/yy Time :
	Cause: ☐ Sepsis ☐ Respiratory failure ☐ NEC ☐ Congenital defects ☐ HIE ☐ Other

Page **1** of **1**

1.3: Variables not included in the CHUK neonatal database that are required specifically for this study

		VARIABLES		
	1	**Patient date of admission**		
	2	**Planned date of discharge**		
	3	**Actual date patient went home**		
		VARIABLES		
4.		Weight on discharge (in grams)		
5		Date the final pre-discharge weight was measured (will be used to calculate average weight gain per day in (mg/day)		
9.		Categories of Ubudehe of the parents or caregivers	1. I 2. II 3. III 4. IV	
1 0.		Who will be the main caregiver after the baby is discharged	1. Mother 2. Father 3. Grandmother/aunt/other family 4. Other non-family member	
1 1.		Main Caregivers level of education	1. No school or started primary school 2. Completed primary school 3. Completed secondary school 4. Completed post-secondary education	
1 2.		Province of origin	1. Kigali City 2. East	

		3. North	
		4. West	
		5. Southern	
3	1	Medical insurance	1. MS 2. RSSB or MMI 3. No insurance 4. Other private (Saham, Britam etc.)	

4	1	Types of Supplement prescribed on discharge and doses.	1. Elementary Iron derivate dose: _____
			
			2. Vitamin D dose: _____
			
			3. Others:
			
			    _____Dose: _____
			
			    _____Dose: _____
			
			    _____Dose: _____	

		Types of feeds on discharge	4. Breast milk exclusively 5. Formula milk exclusively 6. Cow's milk 7. Other 8. Combination	
5	1	Methods of feeding on discharge:	1. Breast only 2. Bottle only	

		3. Cup/spoon only Combined	

Structured phone call interview form

(Read aloud text in blue background)

Section 1: Tracking of phone call attempts

Phone call attempt	Phone number	Relationship to patient	Date/time called	Result (See codes below table)	If not answered, was SMS sent (yes/no)	Was SMS replied? (Yes /no)	Notes
1							
2							
3							
4							
5							
6							
7							
8							

NB: There will be at least 3 attempts per day for 3 days within 2 weeks of the initial attempt

Codes for phone call results:

1. Answered and able to talk = successful

2. Another person answered- main caregiver unavailable to talk

3. Line Busy – not answered

4. Phone disconnected

5. Answered but poor connection and unable to talk

6. Wrong phone number (no relationship with patient – not only list of Section 2)

Duration of successful phone call: _____minutes

Section 2: Documentation of phone call discussion

1.	Date of phone discussion	/
		/

Read aloud: "Hello, I'm Dr. MUBILIGI, a doctor at CHUK hospital and responsible for the study that was presented before you were discharged. Thank you for taking the time to talk to me on the phone. The purpose of this phone call is to find out how you are doing with your baby at home since your discharge from the neonatal unit at CHUK hospital. Your participation will help us improve our understanding about how to best ensure a smooth transition from our unit to home for babies like yours. I'm going to first ask you some questions. Please remember that there are no right or wrong answers. After I ask you these questions, I'm happy to give you advice or answer some of the questions you may have to the best of my knowledge, if this is something you would like.

The first few questions are about the time your baby was in the hospital.

2.	How many days ago have you been discharged from CHUK?	---------------------------

3.	Were you the main caregiver in the hospital?	*1.*Yes *2.*No	
4.	If not, why	*1.* Mom hospitalized in different hospital *2.* Mom passed away after baby was discharge *3.* Mom unable to care for baby for other reason *4.* Other:	

The next questions are about your baby at home and how you are caring for the special needs of your baby:

Some of the questions may be difficult to answer or distressing. If you find any of these questions upsetting, please know that we can stop the conversation at any point that you wish. Are you happy to continue? Yes

5.	Was the baby visited by a CHW since discharge from CHUK?	*1.*Yes *1.*No	
6.	If yes, when was the baby visited by CHW?	*1.*Between 48h and 1 week post DC	
7.	Is your baby still alive?	*2.*Yes *3.*No	
	If neonate died, continue with questions * 8th -30th *. If alive. Move on to the 31st question:		
8.	"I'm sorry to hear about this bad news.	(date)	

	Can you tell me more about this? When did He die?"		
9.	Where did he die	*1.*At home *2.*At a Heath facility *3.*At traditional healer *4.*Other: (on your way to the healthy facility ? etc.)	
10.	Has your baby (did your baby) consulted a healthcare facility since being discharged from CHUK Before he died,	*1.*Yes *2.*No	
11.	Was the baby readmitted in a health facility since discharge from CHUK Before he died,	*1.*Yes *2.*No	
12.	If yes, when was he readmitted to another facility? Before he died,	(Date) = _____days post DC	

13.	What was the reason for admission?	*1.*Apnea
		*2.*Difficulty breathing
		*3.*Fever
		*4.*Feeding issues
		*5.*Poor weight gain
		*6.*KMC
		*7.*Crying/irritability
		*8.*Not passing urine
		   Vomiting/Diarrhea
		   Lethargy/less active
		*9.*Other ( )	

14.	Before DC, were you given an appointment to follow-up Before he died,	*1.*Yes *2.*No	

15.	If yes, when was the appointment	(date)	
16.	If yes, where was the appointment for general newborn care?	*1.*DH: *2.*PH: *3.*CHUK *4.*CHUB *5.*RMH *6.*KFH	
17.	Are you still doing KMC Before he died,	*1.*Yes *2.*No	
18.	If yes, on average how many hours per day (per 24 hours) are you able to do KMC		
19.	If you are/were not doing KMC, why not	*1.*I was told to stop *2.*I did not like it *3.*It was too hard *4.*I don't feel comfortable doing it *5.*Other (not recommanded based on GA or weight)	
20.	Are you still giving him any supplements/medications Before he died,	*1.*Yes *2.*No	
21.	If not, why	*1.*Could not find it *2.*I didn't like to give them *3.*I don't have the money to buy them *4.*I have not yet had a chance to buy them *5.*Other (the baby didn't tolerate them ? etc.)	

22.	What supplements are/were you giving?	*1.*Iron *2.*Vitamin D *3.*Multivitamin *4.*I don't know *5.*Other	
23.	Has the baby started immunizations? Before he died, had he received immunization	*1.*Yes *2.*No	
24.	If he has not started, why not?	*1.*I didn't know he had to *2.*I did not yet go *3.*The nurse refused to give them *4.*Other (not reached weight of above 2 Kgr or did not reach yet PMGA by EED)	
25.	Have you gone for eye screening Before he died,	*1.*Yes *2.*No	
26.	If you haven't gone yet, why not?	*1.*Financial issues *2.*Time *3.*Not wanting to go *4.*Not knowing when or where to go *5.*Other (waiting for CBI update, waiting for DH or HC transfert prossess)	
27.	Has the baby's weight been checked since discharge Before he died,	*1.*Yes *2.*No	
28.	If yes, has/did the baby gained weight	*1.*Yes *2.*No	
29.	If yes, do you know the weight and	Weight	

	when it was	Date:	
30.	How are you feeding the baby Before he died,	**1.**Exclusive breastfeeding **2.**Breast feeding by bottle/cup/spoon **3.**Formula milk **4.**NGT BM **5.**NGT Formula **6.**NGT cow milk **7.**Cows milk by bottle **8.**Other	
31.	How often, on average, do/did you feed your baby within 24 hours?		
32.	At the point of discharge, did you feel ready to be discharged home?	**1.** Yes **2.** No	
32. 2. If not Why		**a.** No milk **b.** No equipment **c.** Fatigue **d.** Fear **e.** I don't know how **f.** No money **g.** No food for mother **h.** Busy with other children **i.** Busy working **j.** Other. (too difficult to care the preemies, worries and anxiety about her/his growth etc)	
3 4	On a scale from 1 to 10 where 10 is extremely difficulty and 1 is very		

		easy, how hard is it for you to care for your baby?		
	3 5		1.	
	3 6	What are the challenges you have encountered to care for your premature baby? Tell me more about this?	1. No milk 2. No equipment 3. Fatigue 4. Fear 5. I don't know how 6. No money 7. No food for mother 8. Busy with other children 9. Busy working 10. No money for medications 11. Other ( )	

Thank you for providing me with the information above. It will help us understand better how babies are doing when they go home.

.		Do you have any specific question that I, as a doctor I can answer? (a way to mitigate the social or emotional risks of the study)	Question about: 1. Feeding method 2. Feeding frequency 3. Weight gain 4. Breathing 5. Colour 6. Illness 7. Medications 8. Passing stools 9. Passing urine 10. Skin problems 11. Other. ()	

Now, if you still have time, I would like to provide you a few advice

3.		Advice provided: (only provide appropriate advice according to above and record here the advice given)	1. Nutrition: breastfeeding frequency 2. Nutrition: breastfeeding technique 3. KMC technique 4. KMC frequency	

		5. Follow-up for ROP	
		6. Nutritional supplements	
		7. correct dosage or administration	
		8. Duration of supplements	
		9. How to find them	
		10. Importance of supplement	
		11. Follow-up for weight and nutrition at health center	
		12. Follow-up for immunisation	
		13. Transport/travel	
		14. Other	
	Was this phone call useful to you?	*1.* Yes *2.* No	
	Have you been able to hear me clearly (quality of connection)	*1.* Yes *2.* No	
	Do you think all parents of premature babies discharged from CHUK should receive a phone call like this?	*1.* Yes *2.* No	
	If no, why not ?	*1.* Other.	

Appendice 5: University of Rwanda/CMHS, CHUK, and RMH ethical approval documents

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 23rd /August/2019

Dr Alexandre MUBIRIGI
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 422/CMHS IRB/2019

Your Project Title *"Perspectives Of Caregivers On Home Transition Of Premature Babies Assessed With The Use Of A Post-Discharge Telephone Call In A Rwandan Teaching Hospital"* has been evaluated by CMHS Institutional Review Board.

| Name of Members | Institute | Involved in the decision | | |
| | | | No (Reason) | |
		Yes	Absent	Withdrawn from the proceeding
Prof Kato J. Njunwa	UR-CMHS	X		
Prof Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS .	X		
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS		X	
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 16th August 2019, **Approval has been granted to your study.**

Please note that approval of the protocol and consent form is valid for **12 months.**

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 23rd August 2019

Expiration date: The 23rd August 2020

Professor GAHUTU Jean Bosco
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:
- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 6th/ 11/2019
No 492/CMHS IRB/2019

Dr MUBULIGI Alexandre
School of Medicine and Pharmacy, CMHS, UR

Re: Amendment Request for Research Protocol

Dear Dr MUBULIGI Alexandre

We thank you for submitting your request for research project amendments in the project titled *"Perspectives of Caregivers on Home Transition of Premature Babies Assessed with the Use of a Post-Discharge Telephone Call in a Rwandan Teaching Hospital and Rwanda Military Hospital".*

After reviewing your request, the amendments have been approved with changes in adding one new research site as follows:

➢ Rwanda Military Hospital (RMH) has been added to Kigali University Teaching Hospital (KUTH), and now there are two study sites.

We wish you success in this important study.

Professor Gahutu Jean Bosco
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR
Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Innovations, UR

CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Quality Health Care
Training & Research

Ethics Committee / Comité d'éthique

October 21st, 2019

Ref.: EC/CHUK/174/2019

Review Approval Notice

Dear Alexandre MUBILIGI

Your research project: "Perceptions of caregivers on transition care of preterm infants using a post discharge phone call at CHUK"

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 18th October 2019 to evaluate your protocol of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your protocol.

You are required to present the results of your study to CHUK Ethics Committee before publication.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

Dr. Rusingiza Kamanzi Emmanuel

The Chairperson, Ethics Committee,

University Teaching Hospital of Kigali

<<University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations>>

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REPUBLIC OF RWANDA
RWANDA MILITARY HOSPITAL

Website: www.rwandamilitaryhospital.rw
P.O. Box: 3377 Kigali, Tel: (+250)252586420, Hotline: 4060
Email: info@rmh.rw

December 20, 2019

Ref.: RMH IRB/071/2019

REVIEW APPROVAL NOTICE

Dear **Dr. Alexandre MUBILIGI**
University of Rwanda

Your Research Project: **"Perspectives of Caregivers on Home Transition of Premature Babies Assessed with the Use of a Post-Discharge Telephone Call in a Rwandan Teaching Hospital and Rwanda Military Hospital".**

With respect to your application for ethical approval to conduct the above stated study at Rwanda Military Hospital, We are pleased to confirm that the RMH/Institutional Review Board (IRB) has approved your study. This approval lasts for a period of **12 months** from the date of this notice, and after which, you will be required to seek another approval if the study is not yet completed.

You are welcome to seek other support or report any other study related matter to the Research office at Rwanda Military Hospital during the period of approval.

You will be required to **submit the progress report** and any major changes made in the proposal during the implementation stage. In addition, you are required to **present the results** of your study to the RMH/IRB before publication.

Sincerely,

Prof. Alex M. Buteera
Colonel
Chairperson Institutional Review Board, RMH

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![WMA logo]

The Norwegian Medical Association
DEN NORSKE LEGEFORENING

Course Certificate
Postgraduate and Continuing Medical Education

Alexandre Mubirigi

Fundamentals of Medical Ethics

Oslo, 15 June 2019

The course discusses the role of ethics in medicine, how ethical issues can be recognised when they arise in medical practice and how to deal with these issues in a systematic manner. The Course is accredited by the Norwegian Medical Association with 8 hours in postgraduate and continuing training for all specialties.

Course coordinator

The Norwegian Medical Association

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