Parental care provided to newborn infants in neonatal unit at hospital level- A qualitative study on parents 'experience and perspectives.

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DECLARATION

I declare that this Dissertation contains my own work except where specifically acknowledged.

Agnes Mukaruziga

Signed…….

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I would like to thank my family for all their support in the period of my research. I also thank my supervisors for their patience, supporting my work and helping me get results of better quality.

I dedicate my work to God, my husband and my two daughters.

ABSTRACT

Introduction and objectives: The admission of a sick newborn is a stressful event for the parents. Preterm infants frequently require an extended period of admission prior to being medically fit for discharge. In resource-limited settings, such as Rwanda, nurse to neonate ratios are low and therefore, Family Integrated Care (FICare) is a necessity, integrating parents as primary caregivers of their sick newborns. This study aimed at identifying the care parents already deliver to their newborns in the neonatology unit, assessing if parents have a desire to deliver more care, and identifying challenges or barriers to FICare and EPCRs.

Methods: A qualitative study was conducted involving in-depth interviews of 15 mothers who had newborns, born between 28 and 32 weeks gestation, and were admitted in the neonatal units of a District and Tertiary hospital in Kigali, Rwanda, from January 2018 to March 2018. Interviews were coded and a thematic analysis undertaken.

Results: Parents reported meaningful package of care they were providing to their newborn infants like feeding newborns, doing activities related to cleanliness and hygiene, giving oral medications. Additionally, parents have expressed interest in providing supplementary care to their newborn, such as measuring weight and taking temperatures. There were many challenges, such as unstable mothers due to problems related to pregnancy or delivery, lack of knowledge and skills in neonatal care, financial limitations, and lack of family support. Parents highlighted the support they were expecting from healthcare providers (HCPs), especially the need of communication about health conditions of their neonates. They were also eager to learn more from HCPs regarding neonatal care.

Conclusion: This study has shown that parents were actively involved in provision of care to their newborn babies and were eager to learn more about newborn care from healthcare providers. It has also revealed various social barriers faced by parents, limiting their participation to parental neonatal care. Thus, parental support and improved communication between parents and HCPs are recommended to overcome these barriers to FICare and EPCRs and to enhance participation of parents to the newborn care provision.

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KEY WORDS (MeSH): Neonatal unit, infant, preterm, parents, family integrated care.

LIST OF SYMBOLS AND ACRONYMS

CHUB: University Teaching Hospital of Butare
CHUK: University Teaching Hospital of Kigali
ELBW: Extremely Low Birth Weight
EPCRs: Extended Parental Care Roles
FIC: Family Integrated care
HCPs: Health Care Providers
IRB: Institutional Review Board
KFH: King Faisal Hospital
KMC Kangaroo Mother Care
LoS: Length of stay
MoH: Ministry of Health
NICU: Newborn intensive care unit
NISR: National Institute of Statistics of Rwanda
PI: Principle investigator
RDHS: Rwanda Demographic and Health Survey
RSSB: Rwanda Social Security Board

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CHAPTER 1: INTRODUCTION

1.1 BACKGROUND AND LITTERATURE REVIEW

After birth certain neonates require admission to the neonatal unit. In some cases this can lead to an extended hospital stay depending on their clinical condition. During this time, involvement of parents in delivering care will vary depending on the hospital.

Baseline data from 2016 at the University Teaching Hospital of Kigali (CHUK) reveals that out of 2,048 births, 568 (28%) were admitted to the neonatal unit. The mean length of stay (LoS) was 14 days. In order to obtain the range of care and how it can be improved, the attitudes, knowledge and perceptions of parents on neonatal care giving must be observed.

1.1.1 Neonatal care in Rwanda

The Rwandan Ministry of Health (MoH) has produced neonatology treatment guidelines that were released in September 2012. These guidelines are a tool used by health care professionals (HCPs) in order to standardize care (1).

Every five years, the National Institute of Statistics of Rwanda (NISR) implements a survey called The Rwanda Demographic and Health Survey (R-DHS). The latest survey was R-DHS 2014-2015, implemented from November 9, 2014 to April 8, 2015. Perinatal mortality rate was found to be 29 deaths per 1000 pregnancies. Neonate mortality rate was 32 per 1000 live birth. According to the RDHS survey, infant mortality declined from 50 to 32 deaths per 1000 live births between 2010 and 2015 (2).

1.1.2 Levels of neonatal care

Rwandan hospitals provide Level I and Level IIA neonatal care as per equivalent standards in the USA (3). The latest RDHS (2014-15) does not mention who should provide care in terms of the HCP and/or parents (2). Levels of care describe the ability of health care facilities to provide interventional therapies for more at-risk/sick neonates:

> Normal care **t**akes place in the maternity unit, no specialist pediatric care required. Term newborns who are stable and those born between 35-37 weeks gestation who are stable clinically are cared in level I which cares also infants less than 35 weeks gestation before being transferred to a higher level. Level II receives infants of 32 weeks gestation or greater and those with 1500 grams or more with moderate illness. This level provide respiratory support for brief duration and cares infants less than 32 weeks gestation until transfer to the neonatal unit. Level III offers full range respiratory support, advanced imaging and access to pediatric subspecialties. Level IV offers surgery for complex conditions, pediatric medical subspecialists and facilitate transport (3).

1.1.3 Family integrated care (FICare)

There have been many changes in the last 50 years associated with parents and neonatal care. Previously, parents were only allowed to enter the neonatal unit 1 to 2 days prior to discharge due to concerns of HCP about infection control and parental incompetence but the role of parents was improved with introduction of bonding and attachment theories .Even in modern neonatal care units, neonates and parents are separated emotionally, physically, and psychologically. Neonatal care is delivered by HCPs with specialized neonatal skills and this may leave some parents unprepared at the time of discharge. In neonatal unit, many programs, such as family centered care (FICare), have been implemented to promote parent involvement. Parents reported to benefit from this program as they feel more involved in the care delivered to their baby and felt less stressed. FICare is possible and practical and it has many benefits (4–7).

Benefits of FICare are a decrease in the incidence of nosocomial infection, increase in weight gain, and increase in the incidence of breastfeeding at discharge. Increasing parental engagement aids bonding and equips the parent with the skills necessary to be ready for discharge. FICare reduce parental anxiety and stress and reduce length of hospital stay; in addition, FICare improves infant neurodevelopment (8–16). In a resource-limited setting (such as Rwanda) this could have potential benefits as nurse to neonate ratios are low and therefore, delegating tasks to parents could enable nurses to better deliver other aspects of care. However, these parental roles should be accompanied by support and education from HCP.

For newborns with complex needs, a multidisciplinary team is required in addition to skilled nurses and pediatricians (13,17). No evidence found about FICare in low income countries.

1.1.4 Parent's impression and experience of the neonatal unit

Initial parental impression in neonatal unit was found to be full of stress, anxiety, worry, and depression due to neonatal units 'sound and sight, due to the appearance of their neonate who are fragile. In addition, prolonged separation between mother and her infant may induce frustration, impression of failure, guilt and irritability. Some parents are shocked and heartbroken by seeing all the wires on their infants, lying in incubator. Parents may feel helpless, scared, panicked. Event preceding neonatal admission are sometimes unexpected which leave them only emotionally capable of simple observation, it took time to become familiar with the neonatal unit settings. Parents have reported to be challenged by the new experience of having their infant in neonatal unit. The comfort for the parents comes from information got during ward round. Medical staff should update parents frequently about the clinical status of their infants and in addition they should involve parents in the care delivered to the newborns as the care would be incomplete if parental involvement is neglected (6,7,18,19).

1.1.5 Parental needs in neonatal unit

A review of the literature done in Belgium (1990-2008) revealed that the stress of parents who have infants in neonatal is reduced by the information and communication parents receive from medical staff.. The time constraints of neonatal staff sometimes result in parents using other information sources to answer their questions and concerns. Some sources of information are internal (printed material) while others are external (internet, television, radio, journals). The pattern of informational needs change along the course of hospitalization and also depends on the condition of the newborn. When the neonate is in a critical condition, parents will request the chance of survival of their neonate and at the time of discharge, they

will require education about home care. Having a neonate in the neonatal unit creates a need for parents to be comforted while facing the situation they were not prepared for, the stress is for both parents, also fathers should be supported and nurtured as their wives, studies have revealed fathers' feelings of frustration and worry (17,20,21).

1.1.6 Parent's view on nursing support

It has been shown that the stress of parents in the neonatal is less when they are well supported, which is improved by providing them with clear and updated information. Through this stressful experience, parents need open communication and developmentally supportive care. To reduce negative feelings, parents should receive empathy from medical team, they should be answered properly and the care given to their infants must be adequate. Nurses have to determine the support needed by parents (8,18,22).

1.1.7 Parent's confidence to deliver care in neonatal unit

Neonatal units should develop strategies in order to promote parental participation in the care of their child. After delivery, it is common to see mothers not knowing if they belong to the maternity ward or neonatal unit and they feel excluded. Neonatal staff should promote parental participation in the care of their child, day and night, but it was shown that these conditions are not always offered where staff sets limits and controls parents' participation. If involvement of parents is limited to breastfeeding and touching the newborn, parents may feel incompetent. Parental competence in neonatal unit comes from closeness with their infants, good collaboration with nurses, social assistance and having information. HCP should encourage the relation of parent-infant to promote the parent' s control of the infant (23–25).

1.2 JUSTIFICATION OF THE STUDY

It was suggested that visitations, talking to babies, changing diapers, skin-to-skin contact, and taking temperature improves the outcome for neonates and parents during hospitalization in neonatal unit (26). Nurse to neonate ratios are low in Rwanda and therefore, HCPs are strained to provide full and attentive care. Nosocomial infection rates are high and adequate nutrition is difficult to achieve. Engaging parents in extended parental care roles (EPCRs) could improve care and reduce the burden on already overwhelmed healthcare providers.

There is no data in Rwanda regarding the types and quantity of care parents already deliver to their newborns in the neonatal unit, the challenges/barriers parents are facing during care delivery, and no data regarding Family Integrated Care (extended parental care roles).

1.3 RESEARCH AIM

There are three aims to this multi-site, qualitative research project; 1. Identify the care that parents already deliver to their newborns in the neonatology unit; 2. Assess if parents want to deliver more care (EPCRs); and 3. Identify the challenges/barriers to parental care delivery and EPCRs.

1.3.1 Qualitative research questions

Question 1. What care do parents report that they are already delivering to their neonates on neonatal units in Rwanda?

Question 2. What are parental attitudes and perceptions on other aspects of care that parents would like to provide for their admitted newborns?

Question 3. What are the challenges parents experience and perceive in providing care for their sick newborns?

Question 4. How do parents feel that they could be better supported to extend their care-roles and improve the care they deliver to their neonates?

Question 5. What are parental perceptions of the positives and negatives for their neonate, or themselves, in respect to providing EPCRs.

CHAPTER 2: METHODOLOGY

Reporting of this qualitative study has been verified in accordance with the COREQ and SRQR checklists for qualitative studies (27,28).

2.1 Study design

This was a qualitative research study employing semi-structured face-to-face interviews. The principle investigator (PI) undertook the interviews in Kinyarwanda. The data was collected using digital voice recording with additional field notes. Transcription was performed by a trained research assistant and then double checked by the PI. Translation was performed by a research assistant competent in English and Kinyarwanda. The translation was double checked by the PI.

Interviews (29): In-depth, semi-structured, interviews explored the experiences of participants and the meanings that they attribute to them. Researchers encouraged participants to talk freely about issues pertinent to the research question by asking open-ended questions, during in one-to-one interviews. Interviews were open-ended to allow the parents to fully describe their experiences and perspectives from their own point of view.

The interviewer re-ordered or clarified the questions to further investigate topics introduced by the respondent. In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease and to explore personal and sensitive themes. They can also help identify potentially modifiable factors for improving health care.

2.2 Qualitative approach

A phenomenology approach was employed to understand how parental experiences in taking care of their preterm newborns admitted in neonatal unit.

2.3 Study sites:

The study was conducted in two urban government hospitals.

The University Teaching Hospital of Kigali (Centre Hospitalier et Universitaire de Kigali, CHUK), is one of the four government tertiary hospital in Rwanda, a referral hospital located in Kigali. Kigali is a city with a population of 1.2 million and also is the capital of Rwanda, a country of twelve million. CHUK is a teaching hospital for University of Rwanda. As a public hospital, the majority of population served by CHUK uses community insurance which covers 10% of the cost of care. The obstetric department of CHUK conducts approximately 2000 deliveries per year, most of them are high risk deliveries. Neonatal unit of CHUK which could be considered a level II by USA standard (3), has two paediatricians who supervise 3-5 paediatric residents. The neonatal unit has approximately 560 admissions per year and has 20-30 newborns per day. Nursing care is provided by 3-5 registered nurses per shift, minority of them have specialized neonatal training. Infants who are discharged from neonatal unit are followed up at the nearest health facility or they come back to CHUK as there are no services of post discharge home visits available.

Muhima District Hospital (MDH): is a government secondary hospital. MDH is one of the three districts hospitals located in Kigali, the capital of Rwanda. MDH serves 10 Health centers, most of the patients pay 10% of the cost of care as they use community insurance, The obstetric department of MDH conducts approximately 5971 deliveries per year, high risk deliveries are transferred to CHUK Neonatal unit of MDH which could be considered a level I by USA standard(3), has 4 pediatricians and one neonatologist from CHUK who comes once per month for mentorship. The neonatal_unit has approximately 12500 admissions per year and has 30-35 newborns per day. Nursing care is provided by registered nurses per shift, no one has specialized neonatal training. Infants who are discharged from neonatal unit are followed up at the nearest health center or they come back to MDH as there are no services of post discharge home visits available

2.4 Study population

In order to gain a representative sample of viewpoints and perceptions the following populations was gained:

Hospital type: Government tertiary neonatal unit (CHUK) and Government secondary neonatal unit (MDH). Gender: only females were interviewed (fathers were not around during the time of interview). Neonate gestation: 28-32 weeks gestation.

2.5 Inclusion and Exclusion criteria

Inclusion criteria: Parents with neonates 28-32 weeks' gestation age (chosen as they experience prolonged length of stay and therefore need parental care) both male and female from day 0-28 of life, admitted for any reason, during three month study period from January 2018 to March 2018.

Exclusion criteria: Parents who have infants with poor prognosis (with congenital malformations) which would be considered distressing for the caregiver to discuss the research topics.

2.6 Methods of approach

Parents of preterm infants born between 28-32 weeks gestation were found in neonatal unit, they were invited to participate in the study, then they were approached privately in a room near the neonatal unit; the researcher introduced and explained the research to the parent after a brief meeting. Interviews were not influenced by the researcher as she was not taking care of those newborns at the time of interview. It was explained to parents that they would be involved in a study regarding their perspectives and experiences of taking care of their newborns admitted in neonatal unit.

2.7 Sample size (saturation)

Interviews were conducted until the minimal representative sample was reached. Six to twelve subjects are generally suggested as adequate by Guest et al. (30). Saturation is defined not in terms of theoretical development, but simply when information from analysis produces little or no change to the codebook. Each interview was transcribed, translated and coded prior to

proceeding with the next interview. This was to ensure that subjects were not recruited once saturation was achieved, which would be unethical.

2.8 Questionnaire design / interview guide

A semi-structured interview questionnaire was designed specifically for this study. Questions were designed using guidance from Thorogood et al.(31). The questionnaire was piloted on one parent (without recording and/or transcription) to ensure good understanding of the questions and to create a preliminary theme and code book.

2.9 Measurement of the outcomes

Outcomes were measured through in-depth interviews using a semi-structed questionnaire. The interviews of parents were conducted in a quiet room.

Data collection: Interviews were recorded digitally using 2 smart phones**,** one of them used as a backup.

Repeat interviews and review of transcripts:
No repeat interviews were carried out.

Interviewer: The principle investigator (PI) undertook the interviews in Kinyarwanda

Interviewer gender, credentials, occupation, experience and training:
The interviewer (PI) is a female postgraduate student in her final year of her Masters in pediatrics at the University of Rwanda. She has four years of experience in neonatology.

Interviewer relationship to with participants:
There was no prior relationship between interviewer and participants.

Field notes:
Field notes were taken during interviews.

Duration:
Duration of interview was between thirty minutes and one hour.

Translation: Translation was performed by a research assistant competent in English and Kinyarwanda. The translation was double checked by the PI. Back-translation was not performed.

Content analysis. This study employed conventional content analysis. The goal of content analysis was to provide knowledge and understanding of the phenomenon under study (31).

Software: The interviews were transcribed, translated, coded and analysed in Microsoft Excel (32). Using Excel, the transcribed text was divided into "meaning units".

Coding: Condensation is a process of shortening the text while still preserving the core meaning and a code can be thought of as a label: a name that most exactly describes what this particular condensed meaning unit is about. A code is usually one or two words long. New themes were added as interviews progressed. Coding was performed by the PI.

Coding tree: Codes are presented in the final manuscript in the form of a coding tree.

Derivation of themes: A theme can be seen as expressing an underlying meaning (33).

Thematic analysis: Thematic content analysis was performed by undertaking four steps: Step one is to be familiar with the data, step two is to identify codes and themes using excel by searching for repetition, looking for "in vivo" ,metaphors and analogies, step three is coding the data and step 4 is organizing codes and themes for presentation.

2.10 Ethics/study oversight

Risk to subjects: significant physical, social, legal and financial risks were not identified. Emotional risks were possible as we interviewed parents who had neonates with uncertain prognosis. These parents were potentially prone to show anxiety and sadness. To protect participants, they were allowed to choose who could stay with them during the interview, two mothers requested to stay with their next of kin.

No one needed counseling or psychological support. Parents were reminded of their right to limit their participation or withdraw from the research if they became uncomfortable and no withdraw from the study.

Funding & Sponsors: No funding has been sought or gained for this project.

Potential conflict of interest: No potential conflicts of interest for the PI or supervisors.

Confidentiality: Confidentiality was observed by using Unique Patient Identifier codes for each transcript.

Informed consent: Parents were given a verbal explanation of the study and were then asked to sign a voluntary informed consent form in Kinyarwanda..

Academic integrity: The study protocol was approved by the University of Rwanda academic team on the 19th January 2018.

Institutional review board (IRB): **The research protocol was reviewed and** approved by the University of Rwanda IRB (Ref.: No 269/CMHS IRB/2018) and CHUK ethics committee (Ref.: EC/CHUK/695/2018).

CHAPTER 3: RESULTS

3.1 Participants

Parents: Fifteen caregivers of the newborns were interviewed. Fourteen of them were mothers and one maternal aunt, all aged between 20-40 years. Among the 14 mothers, 12 were married and two were single-mothers. The mean of gestation age was 29.5 weeks and the mean of birth weight was 1205 grams.

Interviews: There was no deviation from the study protocol. The mean length of interview was 45 minutes (minimum=30 minutes, maximum= 60 minutes).

Interviews were significantly shorter than the pilot interview. The pilot interview was not recorded, we speculate that mothers were potentially fearful of being recorded which made interviews shorter than anticipated.

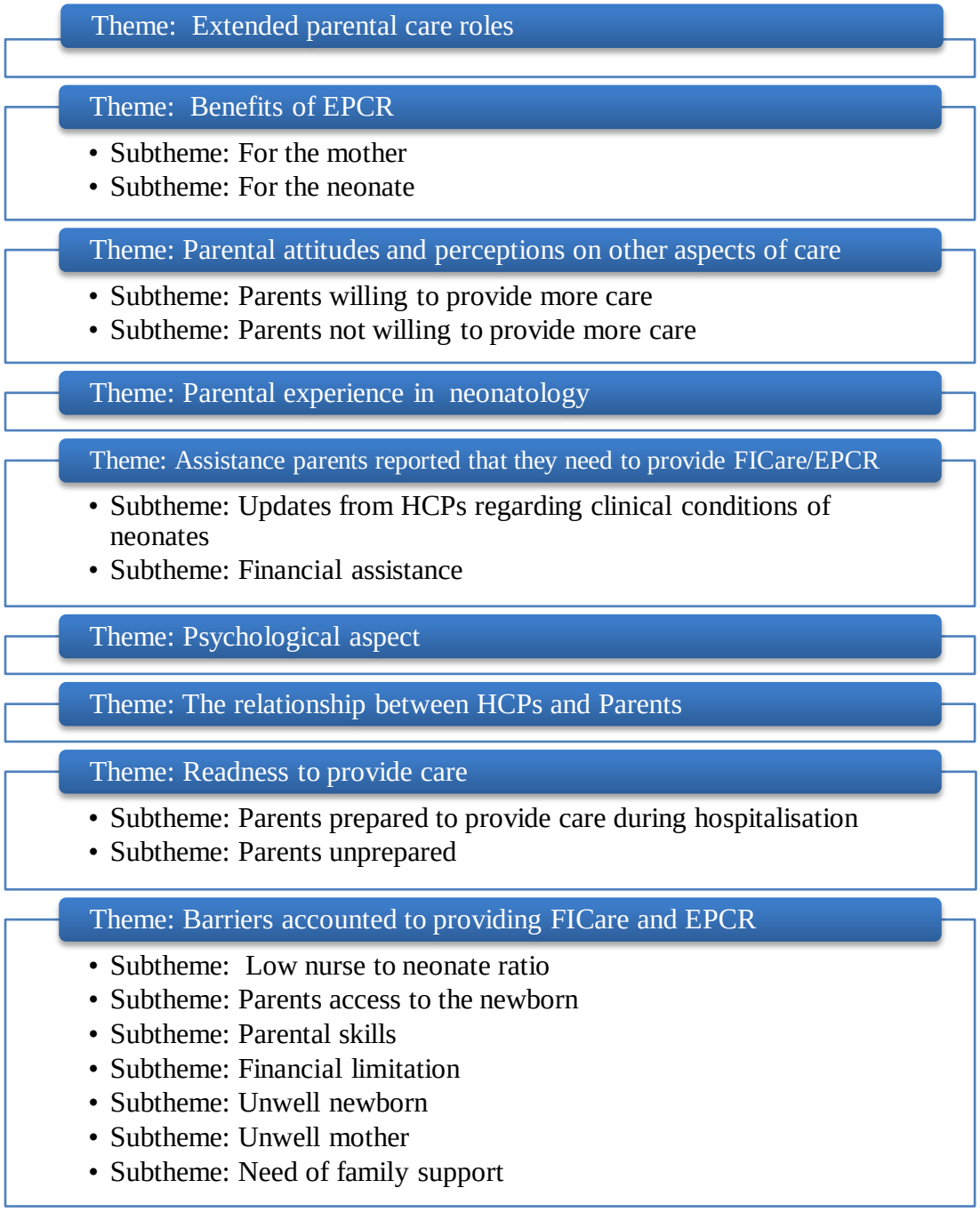
Table 1: Demographic characteristics

	Demographic characteristics	**n= 15**
Neonate	Mean gestation in weeks (SD)	29.5 (±1.45)
	Mean weight in grams (SD)	1205 (±285)
	Mean length of stay in days (SD)	19.8 (±16.4)
Caregiver	**Mother mean age (years)**	24 (±6.09)
	Marital status	
	Married	13 (86.6%)
	Single mother	2 (13.3%)
	Level of education	
	None	4 (26%)
	Primary	8 (53.3%)
	Secondary	2 (13.3%)
	University	1 (6.6%)
	Socio-economic status (Ubudehe)	
	Cat 1 (low)	2 (13.3%)
	Cat 2 (middle)	9 (60%)
	Cat 3 (high)	3 (20%)
	Unknown	1 (6.6%)
	Origin	
	Kigali	9 (60%)
	North	1 (6.6%)
	South	3 (20%)
	West	1 (6.6%)
	East	0 (0%)
	Foreign	1 (6.6%)

3.2 Thematic analysis

During the data collection, the PI interviewed the caregivers in Kinyarwanda. The Transcription and translation from Kinyarwanda to English were performed by a competent research assistant and then the PI checked then the consistency.

Figure 1: Thematic tree



3.3 Theme: Extended parental care role

Parents described the care they were providing for their newborns (Table 2). These tasks were related to cleanliness and hygiene, feeding, bonding, medication and KMC.

Table 2: Tasks reported by mothers

Cleanliness and hygiene	Feeding	Bonding	Medication	Other
Cleaning the newborn Put lotion on the skin Changing diaper Giving bath Check if the newborn has passed stool Washing her/his clothes Checking if the newborn is dirty	Breastfeeding NGT feeding Bottle (formula) feeding	Singing Talking Watching over the newborn	Giving oral medications	KMC

Parents described the type of care they were providing to their newborn in the NICU. Given the fact that parents are the next of kin of newborns admitted in NICU, most of the time they are present, observing, and receiving information from HCPs, but are also taking care of their newborns. Through the series of interviews, the parents expressed their roles in caring the newborns:

"I clean, wash and feed him with so much love "[Interview 12].

"I clean him well when he pooped on himself, I bath him and also I talk to him and sing for him "[Interview 8].

The relationship between parents and newborns strengthens through different ways and it is very important because it sustains the bonding between them. This stimulation of preterm infants by their parents favors the stability of the newborns.

Even if HCPs have good knowledge about the needs of newborns, parents are naturally the best caretaker as they are aware of the essential needs for their newborns and are well motivated to provide care to the best of their ability.

"….they could teach me how to give oral medication and how to take weight… I will know if my baby gained or lost[weight], I would take care of my baby" [Interview 14].

"I care as parent "[Interview 6]

When parents care for their newborn infants, it allows them to stay with the newborn. This has a positive impact in the hospital setting where nurse to neonate ratios are low. The involvement of caregivers results in feeding neonates on time and in terms of feeding has the potential to optimize nutrition.

3.4 Theme: Benefits of EPCR

Involving parents in care delivery is beneficial for both the parents and infants. As parents adapt from being observers to caregivers, this led to several perceived benefits:

3.4.1 Subtheme: For the mother

Neonatal parenthood is stressful; therefore, the parents should be involved in the care of their newborn from the beginning to ensure optimal care during the admission and to gain confidence for a successful discharge plan. This proved to be more beneficial for the parents.

> *"I would stay with my baby* "[Interview 5].
> *"If I am the one who provides care to my child, I could know him better"*[Interview 2].

Some mothers showed the benefits they gained by providing care to their newborns such as learning by observing the HCP.

> *"I could get great enough. Because, I could know how to take care of my child without any guard. I could know how to make it"* [Interview 3].

By providing care, parents are allowed to stay in the neonatal unit and it reduces their stress as they are aware of their newborns status. Parents have time to ask questions, participate actively in ward rounds and have the opportunity to be updated about the progress of infant's condition.

3.4.2 Subtheme: For the baby

The parents described benefits they felt that their newborn would gain through parental care delivery.

> *"And the child could benefit from parents' care since he feels his mother's love"* [Interview 3].
> *"It could help in his growth, knowledge and get used to me"* [Interview 6].

Generally, the care delivered by a relative is meaningful, as it increases bonding between the parent and newborn. Normally, the baby is fed and cleaned by a parent who will continue care at home and this has a positive impact on continuity of home health care.

3.5 Theme: Parental attitudes and perceptions on other aspects of care

3.5.1 Subtheme: Parents willing to provide more care

In the neonatal unit parents reporting being able to provide more care when they are allowed to participate in the care of their newborn. These extended parental care roles included taking temperature, oxygen saturation, give oral medications and weighing the baby.

> *"Yes, they showed us many things like how to use those measurements, and we are capable to do them ourselves"* [Interview 3].
> *"There are some medicines they showed me how to use them, and, now I know how"* [Interview 8].

"Yes, like checking temperature, weight, measure oxygen saturation" [Interview 10].

Engaging parents in caring for their newborn gives them the opportunity to have a more positive experience with their newborns. Parents also transition from observers to active caretaker. This may have impact on important care monitoring vital signs, daily measures and updates and timely medication administration which are often very challenging with low nurse to patient ratios.

3.5.2 Subtheme: Parents not willing to provide more care

Infants in the neonatal unit frequently have complex care needs. Some parents described some of the difficulties that they perceive in providing care to their newborns. They have demonstrated that the help of HCP is very crucial.

> *"Nothing else I can do apart from breast-feeding him when they allow me to do so. I cannot do anything without doctor's help"* [Interview 6].

This highlights the role of HCPs as the educators of parents. The parents need consistent support during the neonatal admission and throughout the course of hospitalization, which strengthens parental ability to care their newborns after discharge. Parents are not trained HCPs and though well positioned to provide care this requires support and education.

3.6 Theme: Parental experience in the neonatal unit

Some mothers also described personal experiences about the impression they had when they saw their infants in the incubator, a material which is new for them

> *"Personally, I feel so depressed when I always see him naked. I want him to wear clothes* [Interview 15].
>
> *"When he (the baby)was still in incubator, I used to feed him and he vomited a lot* [Interview 6].

Maintaining the temperature of the premature infant requires the use of incubators where newborns frequently are nursed naked and fed in lying position. Vomiting and reflux is common in preterm infants and to be decreased, infants should be lying on inclined plane. The comments from these mothers may reflect poor communication between the parents and HCPs. The reason of this delayed communication is unknown. It may be due either to the absence of the mother during ward rounds where most of explanations would be delivered or to poor communication since the few HCPs have to take care for a large number of newborns. This negatively impacts the different views that parents may have regarding the management of their newborns.

3.7 Theme: Assistance parents reported that they need to provide FICare/EPCR

3.7.1 Subtheme: Updates from HCPs regarding clinical condition of neonates

The stress coming from preterm birth is common for all parents; however, parents report that this stress becomes exacerbated when they are not updated on the management of their newborns.

Having a preterm infant should not be a reason for parents to be treated as visitors. They should rather be involved in care of their infants.

"I would like to have explanations about the progress of my baby" [Interview 1].

Some parents highlighted the necessity of adequate time for more communication between parents and HCPs. Without communication, better and sustainable care cannot be achieved, and the parents can potentially become more anxious, discouraged and scared.

Therefore, the parents should be educated and counseled accordingly and in a timely manner about infant care to insure consistency even after the time of discharge.

"The help from them would be approaching me and discuss so I learn how to care the child. If I could get fifteen (15) minutes of discussion it would be enough" [Interview 3].

It should not be good for HCPs to have updates of the baby only without paying attention on the condition of the mother. Parents may not be comfortable talking concerns faced during neonatal stay.

"Sometimes, I try to get breast-milk and I get few, and I worry, I didn't inform the doctor about that" [Interview 8].

Parents may feel intimidated and nervous due to lack of experience of being in the neonatology,. Lack of breast milk is common when the mother is stressed. To address this obstacle, it requires HCP to be close to parents and listen to them and teach them how to care a premature newborn.

3.7.2 Subtheme: Financial assistance

Some of the interviewed mothers had mentioned the financial assistance they were waiting from the hospital.

"We would like to be helped by the hospital, we have twins and we do not have enough milk" [Interview 7].

"They should avail medications according to the money we have" [Interview 9].

Due to their prematurity, preterm infants are predisposed to have many complications requiring medications and having a preterm delivery is not an event parents were prepared for. Parents may be challenged to buy medications. Ideally preterm infants should be fed with breast milk but when they are twins, it becomes difficult to the family to feed them adequately, without supplementing with formula milk..

3.8 Theme: Psychological aspects of EPCR

Some parents are not confident enough to assume the responsibility of taking care of their premature babies and having a baby hospitalized in neonatology is stressful.

"Yes, I am comfortable to take care of my baby but sometimes I feel sad because of my child's sickness" [Interview 1].

"I am anxious, I have been here for long time" [Interview 2].

Length of stay in neonatology may be prolonged due to level of prematurity of the infant and parents may be tired of waiting. Length of stay range from days to months and it contributes to the parental stress. The clinical status of the neonates admitted in neonatal unit varies daily and sometimes they may experience a sudden deterioration even though they had signs of improvement previously.

3.9 Theme: The relationship between HCPs and Parents

Two of the interviewed parents had concerns about the lack of updates from HCPs and they perceived it as being unfair to them. One of them mentioned HCP are sometimes not available to update parents and in case they are called, they do not respond.

"Like measuring his weight in my absence and lack of updates from doctors, because all are not same kinded" [Interview 14].

"I faced the challenges when I called upon the doctor and did not come" [Interview 9].

Due to the low ratio of HCPs to neonates, it is possible that parents may perceive the absence of HCP attention as a lack of kindness. Ideally, every newborn should have her own HCP, however, this is not possible in the resource-limited setting given the newborn-HCP ratio. Considering the fact that there are few HCPs and all the tasks that they have to fulfil, such as giving medications and admission of new infants, some tasks are performed in the absence of the parents, and so may go unseen by parents.

3.10 Theme: Readiness to provide care

3.10.1 Subtheme: Parents prepared to provide care during hospitalization

In order to be ready at the time of discharge, parents need to be familiar with the care delivered to their newborns. Readiness must start while the newborn is still in the hospital and the parents have to be observed by the HCP and the parents can be supported.

"I feel I can do it; because he is calm once he got milk and I feel comfortable for that" [Interview 8].

It is easy for some parents to deliver care to their newborns when they are stable or not critically ill or if the parents have experience with a preterm baby in the past. However, other parents highlighted the need of HCP supervision.

"Yes [I can provide care], when I am supported by medical staff" [Interview 1].

"As we were educated by the medical staff I became confident and I started taking care of my baby" [Interview 12].

A clear guidance of parents taking care of their newborns admitted in NICU is the foundation of successful transition from hospital to home care. The parents must be trained by an HCP ensuring the sustainability of good care even in absence of HCP.

3.10.2 Subtheme: Parents unprepared to provide care

Delivering care to premature newborns requires some experience, which is lacking for most mothers. There were also physical challenges such as mothers who had not physically recovered from labour and/or illness.

> *"I see no ability for me to do so"* [Interview 7]

> "*It is not easy [to take care of the newborn] ....I have not yet recovered from difficult labor"* [Interview 10].

The consequence of not involving parents in the care delivered to their newborns while admitted, is that parents may not know how to feed their newborns, hold them, clean them, and how to avoid hypothermia (which has a negative impact on their growth) which are all required at discharge.

3.11 Theme: Barriers accounted to providing Family Integrated Care (FICare) and extended parental care roles

3.11.1 Subtheme: Low nurse to neonate ratio

Parents reported that they had a strong desire to extend their care roles, but they were limited by the low number of HCPs, in particular nurses. The HCPs have many tasks to perform which resulted in a delay in educating parents on care.

> *"Sometimes the feeding is delayed due to absence of nurse who was supposed to replace the NGT because she is taking care of other sick baby"* [Interview 1].

Therefore, HCPs may need to minimize some tasks and give more time to parents.

3.11.2 Subtheme: Parents access to the newborn

In order to provide EPCRs, mothers need to have easy access to their newborn. Security is important, however, locking the doors of the neonatal unit, such as is the case at CHUK, might inhibit mothers accessing to their newborns. Two mothers reported challenges of access to their newborn because of locked doors.

> *"When someone does not open for you [door], this may lead to the late feeding of the child"* [Interview 11].

> *"Someone should be available to open for us especially during the night "*[Interview 9].

The impact of lack of access may cause late care delivery to their newborn. In this case, if the baby is not fed on time, there could be a fluctuation in blood sugar level and/or long-term under nutrition. Normally, the security doors are often opened by nurses. However, if the nurses are busy, they may not open promptly. Therefore, if the mothers are unable to provide EPCRs this may cause the nursing staff to become further overloaded because the mothers can't provide the care, thus worsening the situation.

3.11.3 Subtheme: Parental skills

Mothers reported that they felt that they did not have the skills required to provide care to their ill newborn to the same standard as HCPs. They may under estimate themselves due to lack of skills.

"I was reluctant to touch my baby who was small and fragile and I was not skilled" [Interview 12,].

"I do not have skills about feeding the baby, sometimes the NGT is blocked" [Interview 4].

When the parents are not confident, they may feel like they have lost their role as parents to care for their newborn. This feeling of being excluded may make parents to be unprepared at discharge

3.11.4 Subtheme: Financial limitations

When a baby arrives prematurely the family are frequently not yet prepared to care for the newborn, e.g. financially or with other resources. During the neonatal stay, parents face many challenges such as financial limitations.

> *"I guess that it is enough but sometimes they give me medical prescription without ability to buy them. They are prescribed as they are necessary but I don't have means to buy them"* [Interview 4].

> "*Sometimes I do not have formula milk for fortification"* [Interview 4].

> "*His clothing and milk are over, I feel depressed"* [Interview 6]

Premature babies frequently need supplementary calories and nutrients for the growth, so they may need breast milk fortifiers and other nutritional supplements. For parents who are financially limited, it is a challenge to buy these supplements (iron, vitamins, etc.) as they are very expensive. Without these resources the parents are unable to participate in providing this aspect of care for their admitted newborn.

3.11.5 Subtheme: Unwell newborn

Parents reported a desire to extend their care roles and provide FICare, but they were sometimes anxious because the baby was sick or in critical condition. Vomiting was a particular concern, which highlights the need for education and support as reflux and vomiting are almost universal in premature infants.

> *"Yes, I can provide care except when the baby is critically ill. Sometimes the baby may vomit or have difficulties in breathing"* [Interview 5].

Babies born prematurely have particular physical needs and are at risk of intermittent complications related to their prematurity. They require medical support and interventions and it becomes difficult to the parents who are not skilled, as medical personnel provide care to the infants. Sometimes, they may need to be fed by the HCP due to their clinical condition.

3.11.6 Subtheme: Unwell mother

Some infants are delivered prematurely due to the medical condition of the mother. These mothers may then be requested to provide care of the newborn after delivery. The health of the mother may be a barrier to providing this care

"As parent, I can't provide care because I got sick after delivery" [Interview 9].

"I cannot do anything for them, because, I am sick" [Interview 13].

This has an impact on the mother and the newborn. It is difficult to the mother who is not stable to produce breast milk, feed on time, clean the baby, provide KMC. Fathers should be encouraged to be involved in the care delivered to the infant.

3.11.7 Subtheme: Need of family support

Mothers frequently reported that they wanted to provide care, but they were limited by the fact of being alone.

"Being alone without help from others contributes to my lateness for different appointments with the doctor". [Interview 15].

"I feel helpless when I miss someone to help me "[Interview 11].

The impact of having a mother caring for her newborn alone can contribute to poor communication between HCPs and the mother. In this case, the mother is not always present during ward rounds to ask questions, be educated, and supported, she may be exhausted due to several tasks attributed to her HCPs may check the newborn while the mother is absent. This may have a negative impact on both the mother and newborn.

CHAPTER 4: DISCUSSION

The aim of this project was to identify the care that parents already deliver to their newborns in the neonatology unit, to assess if parents want to deliver more care and to identify the challenges or barriers of parental care delivery. Through 15 semi-structed interviews, we identified nine themes.

4.1 Extended parental care roles

The study found that parent's participation in their infants care varied considerably, ranging from giving medications, feeding, and hygiene. This is not surprising as we have low nurse to neonate ratios in the neonatal units in Rwanda. No other research found about levels of care in low income countries. Our study was consistent with other studies on the fact that parents and their sick babies should be kept together and ensuring that parents participate actively in their baby's care. It was shown that parental participation has a considerable impact on a newborns health and outcome as it establishes bonding. This study provided insight into how parents experience their role and showed their desire to deliver care to their newborns admitted in neonatology which is consistent with the findings of other studies (5,9,10,26).

4.2 Benefits

Some parents reported that when a newborn is fed by the mother, both the mother and infant benefit. Parents gaining skills and babies feeling their parents' love. The care delivered by parents, increases breastfeeding rate and weight gain, it decreases parents stress, nosocomial infection, important decrease of respiratory support time and rate of readmission, it enhances bonding between parents and their infants and provide good neurological outcome which is consistent with the findings of other studies which is in agreement with other studies, has many benefits like good neurological outcome and great weight gain (8–10,12,13).

We found that most caretakers were mothers; some were alone despite their poor health after delivery. In Rwandan culture, it is the mother's responsibility to take care of the newborn, so there should be no separation between the mothers and their infants. It should be advantageous to keep mothers and infants together and involvement of fathers should be encouraged (9,14,34).

4.3 Parental attitudes/perceptions on other aspects of care

Another interesting finding was that some parents have shown interest of being involved in providing more care. EPCRs that parent reported wanting to undertake included taking the temperature and weighing their newborn. Involving parents in care activities and assisting in the neonatal unit makes them ready at the time of discharge and is an important responsibility of HCP. At the time of admission, HCPs may be busy and explaining all details to the parents may be delayed which leads to the parental stress making them unprepared to deliver care. In addition parents have highlighted what they expect from HCPs such as updates on the health of their newborn. They wished for the HCPs to be close to them and to provided time for them, parents

wished to receive emotional support from the HCP, have clear information and to be encouraged to give care to their infants this had similarity with other studies (7,35,36).

4.4 Relation parents-HCP

There was a finding where parents mentioned the kind of support they wanted from HCPs. They wanted to be treated kindly with a good relationship between them. Parents may feel vulnerable if not well treated by the medical staff, parental emotions should not be ignored; there was correlation between their level of depression and the support they received from nurses (18,37).

4.5 Prepared to deliver more care

We found that most parents were prepared to deliver care to their newborns; In order to be ready, some parents mentioned the assistance they were waiting from HCP and the two mothers who were not prepared to deliver care was due to clinical instability after a difficult delivery. The study done by Christina Larsson et al. has similar findings where parents were not ready at the time of discharge due to lack of support, information and preparation (14).

4.6 Barriers

The parents reported that having their room far from the NICU has a negative impact on the extended parental care role. If the mother is discharged from maternity and the baby is still hospitalized in neonatology, care is not delivered adequately due to lack of free access to the neonatal unit, as it is always locked. Our findings were consistent with the study done by Helena Wigert at al. showed that involving parents in care administration is difficult when there is no space reserved for them near the baby's room. Another study done by Russell et al. commented on the positive feelings of parents when allowed to have access to the unit; it increases the bond between infants and their parents (25,36).

4.7 Assistance needed

We found that parents need more assistance during neonatal stay; they have specific information and communication needs. Having sufficient information and frequent updates regarding their baby's health during the neonatal hospitalization is essential. The study done in 2009 in Belgium by Sofie de Rouck et al linked parents having specific information regarding their newborn to a reduction in emotional impact during this period of uncertainty. Parents also wish HCPs to be interested in their infants' wellbeing by being asked about their clinical status. This was shown to provide emotional support and it enhances closeness (8,20).

We found that parents were willing to take care of their newborns but believed that they lacked skills to deliver care as they were very small and sick. Seeing HCPs take care of their newborns gives them more confidence as it is recommended that parent and staff relationships should be respectful and supportive to encourage parental participative (9,38).

4.8 Psychological aspect

In our study, it was found that some parents expressed that having a preterm baby in neonatology aroused negative emotions and anxiety due to losing the chance to bring baby home right away after birth. They did not imagine it would look like that; it can be a difficult time for the whole family. During this time parents need to be nurtured and supported in order to prevent trauma

and anxiety, it was found to be beneficial to babies, to parents and to the staff of neonatal unit. Some parents reported that they were not ready to deliver care to their premature baby and this has contributed to their sadness and anxiety. The stress of parents who have infants in neonatology may also come from separation between mother and infant, which also has short and long term complications as it was revealed by other studies (7,39).

4.9 Strengths and Limitations

4.9.1 Strengths of the study

This is the first study done in Rwanda regarding parental care provided to newborn infants in neonatal unit. A qualitative study approach was used, which is the best to avail rich data for the topic.

4.9.2 Limitations of the study

This study was done in urban setting, 60% of participants were coming from Kigali city, only 40% were transferred from rural areas, there is no data from Eastern Province. Only mother's participated and possible explanations for the absence of fathers were that interviews were done during working hours and that they were less present in the neonatal unit. Including fathers would have been interesting and presented different needs and approaches.

In-depth interviews were undertaken; focus group could have given more comfort to the participants and could have enabled their expression on different viewpoints which were not possible in face-to-face interviews. However, focus-groups have their own limitations and were not feasible during this project.

Interviews to be conducted in Kinyarwanda, transcribed then translated in English may lead to the loss of important information. However, both the Kinyarwanda and English text were read during coding and thematic analysis, by a native Kinyarwanda speaker who undertook the interviews therefore this loss of meaning was minimized.

4.10 Future research:

A study using the same methodology exploring nurses' perceptions could be beneficial.

4.11 Clinical recommendations

HCPs and parents should know that FICare is feasible and has good outcome for HCPs, parents and their infants. HCPs should be aware of the benefits of FICare which will encourage them to provide education and support required to enable families to be part of the care team. It should be a respectful and empathic relationship between HCPs and parents. Parents should be assisted psychologically if needed. Fathers should be encouraged to support their spouses during neonatal stay. To be ready at the time of discharge, parents should be involved in the care of their newborns from admission. Parents have demonstrated their desire of providing more care which should be taken into consideration due to a short number of nurses in our settings.

CHAPTER 5: CONCLUSION

This study provides new insight into what parents need during neonatal hospitalization. It has identified their perceptions, thoughts and perspectives regarding the care delivered to their newborn infants. This is important but future studies should be done that include parents from different hospitals, varying backgrounds, and different social economic status in order to have a wide understanding of parental needs during neonatal hospitalization.

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APPENDICES

Appendix 1: Baseline data questionnaire

PATIENT	Name of baby:					Hospital ID:				
Caregiver being interviewed	☐ Mother ☐ Father ☐ Job ☐ No job									
Single	☐ Yes ☐ No									
Parents' age	☐ less than 20 yrs ☐ 20-30 yrs ☐ 30-40 yrs ☐ more than 40 yrs									
Level of education	☐None ☐ Primary ☐secondary ☐ University									
Ubudehe	☐Cat I ☐Cat II ☐ Cat III ☐Cat IV									
Province of origin	☐ Kigali ☐North ☐ South ☐East ☐Ouest									
Number of children	☐ First ☐ 2-5 ☐ more than 5									
Length of hospital stay	☐ 0 day ☐1-3 days ☐4-7days ☐ 10-20days ☐more than 20 days									
Date of interview										
Time of start of interview										
Time of end of interview										
HISTORY	Sex:	☐ M ☐ F	DOB:	dd/mm/yy			GA:		Weeks	
	Birth place: ☐Tertiary Hospital ☐ District ☐ HC ☐ Home ☐ Other									
ADMISSION	Date:	dd/mm/yy	BW:	g	HC:	cm	L:	cm	Temp:	^{o}C
FEN										
	☐ Regained BW; if yes, Date:		dd/mm/yy	Mother poor breast milk supply>7 DOL: ☐Yes ☐No						
	Feeding mechanism		☐ NGT ☐ EBM expression							
PRIMARY DIAGNOSIS										

Appendix 2: Semi-Structured Interview Script

Research Question 1. What care do parents report that they are already delivering to their neonates on neonatal units in Rwanda?

Research Question 2. What are parental attitudes and perceptions on other aspects of care that parents would like to provide for their admitted newborns?

Research Question 3. What are the challenges parents experience and perceive in providing care for their sick newborns?

Research Question 4. How do parents feel that they could be better supported to extend their care-roles and better care to their neonates?

Research Question 5. What are parental perceptions of the positives and negatives for their neonate, or themselves, in respect to providing EPCRs?

Comments in brackets reflect the research question being investigated

Icebreaker questions (not to be included in the analysis)	
(1) When did you come to see your baby for the first time?	Icebreaker
(2) How did you choose your child's name?	Icebreaker
Research questions (to be recorded, transcribed and translated)	
(3) Do you feel comfortable to take care of your baby?	RQ1
(4) Do you think YOU (as a parent) are able to provide care to for your baby here in the hospital?	RQ1
(5) What challenges do you face while taking care of your baby?	RQ3
(6) What are you able to do for your baby?	RQ1
(7) Do you think it is enough?	RQ2
(8) Is there anything more you wish to do for your baby?	RQ2
(9) Can you think of any barriers/challenges that YOU might have if you wanted to provide more care to your baby?	RQ3
(10) How are you helped when you are facing those challenges? Do you think it is enough?	RQ4
(11) What support do you need from the nurses and doctors to better look after your baby?	RQ4
(12) Are there any of the day to day activities that you see the doctors and nurses do that you think you may able to do for your baby?	RQ2
(13) If you did these extra things/activities for your baby, why might it be good for YOU?	RQ5
(14) If you did these extra things/activities for your baby, why might it be good for YOUR BABY?	RQ5

Appendix 3: Consent forms

Consent form for participation in a study on "Engaging parents in extended parental care roles"

Neonate Name/ID: _____ Date: -_____

By signing the form below, I confirm that the consent form has been explained to me in terms that I understand.

I consent for allowing my newborn baby to be involved in this study. I understand that the information may be used in the medical record of my child, for purposes of medical teaching, or publication in medical textbooks or journal and electronic publications. By consenting to this study participation I understand that I will not receive payment from any party. Refusal to consent to this study participation will in no way affect the medical care my child is receiving or will receive.

I understand that the results of this study may be read by members of general public, in addition to scientists and medical researchers that regularly use these publications in their professional education. Although my baby's information will be used without identifying information such the name of child, I understand that it is possible that someone may recognize that my child had participated in such study. If I have any questions or wish to withdraw this consent in the future, I will contact:

1. Dr Agnes MUKARUZIGA: mukarnesaa@gmail.com, +250 788 850 071 or
2. Dr Faustine AGABA: faustineagaba@yahoo.fr, +250 788 438 837

Names of Caregiver: _____ Names of Witness: _____

Signature: Signature:

AMASEZERANO YO KWEMERA KUJYA MU BUSHAKASHATSI KU BUSHAKE

"Gufasha ababyeyi kwinjira mu gikorwa nyirizina mu buvuzi buhabwa abana babo barwariye mu bitaro byita ku mpinja"

Amazina y'uruhinja/Nomero : _____ Itariki : _____

Mbere yo gusinya iki cyemezo, nabanje gusobanurirwa ibirimo mu rurimi numva.

Ndemerako amakuru y'uruhinja rwanjye yakoreshwa n'abaganga mu bushakashatsi.

Maze gusobanurirwa n'abaganga ko amakuru y'uburwayi bw'umwana wanjye akenewe mu gufasha abandi baganga kungurana ubumenyi ndetse no gufasha abandi bana barwaye nk'uwanjye kuvurwa byisumbuyeho, nemeyeko amakuru y'uburwayi bw'umwana wanjye yakoreshwa muri ubu bushakashatsi. Nemeyeko ibizava muri ubu bushakashatsi bizakoreshwa mu bitangazamakuru byanditswe cyangwa bikorera kuri Murandasi ndetse n'ibitabo byose bikoreshwa mu kwigisha abaganga. Ndabyemeye, ariko nta gihembo nteze guhabwa ndetse ndamutse ntabyemeye nziko nta ngaruka byagira ku buvuzi umwana wanjye ahabwa.

Nasobanuriwe ko ayo makuru abasha gusomwa n'abandi bantu bose bakoresha ibi bitabo cyangwa ibitangazamakuru bya kiganga ariko byose mu rwego rwo kwigisha. Nziko n'ubwo nta mazina y'umwana wanjye azatangazwa, hari ubwo aya makuru ashobora gutuma abantu bamenyako umwana wanjye yagiye muri ubu bushakashatsi ariko ntacyo bitwaye. Ndamutse ngize ikibazo cyangwa nshakako uyu mwanzuro mfashe uhinduka, nzitabaza :

1. Dr Agnes MUKARUZIGA: mukarnesaa@gmail.com, +250 788 850 071 cyangwa
2. Dr Faustine AGABA: faustineagaba@yahoo.fr, +250 788 438 837

Amazina y' Umubyeyi (umurwaza) : _____ Amazina y'Umuhamya: _____Umukono Umukono

Appendix 4: University of Rwanda IRB approval

UNIVERSITY OF RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 23rd /07/2018

Dr MUKARUZIGA Agnes
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 269/CMHS IRB/2018

Your Project Title ***"Parental Care Provided To Newborn Infants In Neonatal Unit At Hospital Level- A Qualitative Study On Parents' Experience And Perspective"*** has been evaluated by CMHS Institutional Review Board.

		Involved in the decision		
			No (Reason)	
Name of Members	**Institute**	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 Gisboma 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 17th July 2018, **Approval has been granted to your study.**

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

EMAIL: researchcenter@ur.ac.rw P.O. Box: 3286, Kigali, Rwanda WEBSITE: http://cmhs.ur.ac.rw/

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,

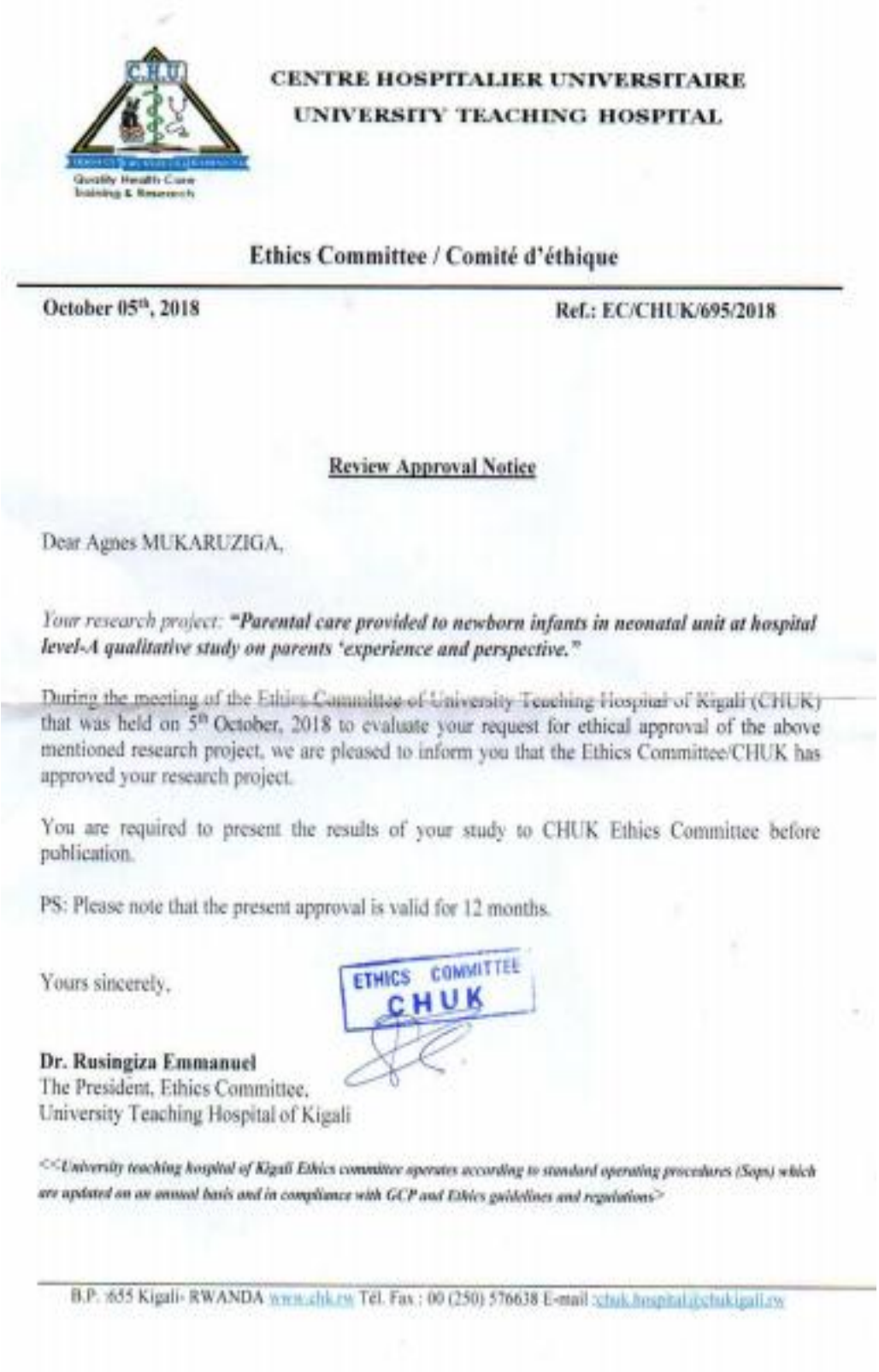
Date of Approval: The 23rd July 2018

Expiration date: The 23rd July 2019

Professor Kato J. NJUNWA
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

Appendix 5: CHUK IRB approval



CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Quality Health Care
Training & Research

Ethics Committee / Comité d'éthique

October 05th, 2018 **Ref.: EC/CHUK/695/2018**

Review Approval Notice

Dear Agnes MUKARUZIGA,

Your research project: ***"Parental care provided to newborn infants in neonatal unit at hospital level-A qualitative study on parents 'experience and perspective."***

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 5th October, 2018 to evaluate your request for ethical approval of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your research project.

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,

ETHICS COMMITTEE
CHUK

Dr. Rusingiza Emmanuel
The President, 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>

B.P. 655 Kigali- RWANDA www.chk.rw Tél. Fax : 00 (250) 576638 E-mail :chuk.hospital@chukigali.rw

Appendix 6: Muhima DH IRB approval

REPUBLIC OF RWANDA

Kigali, October 2nd 2018

KIGALI CITY
NYARUGENGE DISTRICT
MUHIMA HOSPITAL
P.O. BOX 2456 KIGALI
Tél. /Fax : +252 50 37 7
E-mail : muhima.hospital@moh.gov.rw

Agnes MUKARUZIGA

Re: Your request for conducting a research at Muhima District Hospital

Dear **Agnes**

Reference made to your letter received on September 25th 2018 requesting to conduct the research at Muhima District Hospital on Parental care provided to newborn infants in neonatal unit at hospital level-A qualitative study on parents' experience and perspective.

I would like to inform you that your request is approved.

Yours sincerely,

MANIRAGUHA YEZE Aimé Victoire

Chief Ethic Committee

MUHIMA HOSPITAL - ETHIC COMMITTEE -

Cc: - Clinical Director
- Director of Nursing

Appendix 7: NIH Certificate

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **MUKARUZIGA Agnes** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 10/25/2017.

Certification Number: 2537511.