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**Exploring the context, roles and experiences of  
mothers in caring for their inpatient sick newborns in  
Nairobi, Kenya: an ethnographic approach.**

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**B.A. (Anthropology), MSc (Medical Anthropology)**

A thesis submitted in fulfilment of the requirement for the degree of Doctor of Philosophy  
(PhD)

Open University, UK

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## **Abstract**

Little progress has been made in reducing deaths among newborns. Newborn morbidity and mortality can be prevented through the timely provision of combined health systems interventions and access to high-quality inpatient and supportive care. Additionally, recent evidence has demonstrated the importance of social factors to the survival of sick newborns. The involvement of parents through family centred care, as well as maternally delivered interventions, have been shown to have positive outcomes for mother and baby, but in debates around the quality of care for newborns the voices of mothers, particularly in low and middle-income countries, are rarely heard.

Using an ethnographic approach, this study critically examines the roles and experiences of mothers of hospitalized sick newborns in two newborn units in Nairobi, Kenya. Data collection involved non-participant observations, discharge in-depth interviews and narrative interviews with mothers 2-6 weeks post-discharge. Data were collected over 3 years and analysed iteratively using a grounded approach.

The study revealed striking differences in the structural, cultural and socio-economic context of the two newborn units and their clientele. In both hospitals, the mothers played a role in providing care for their babies but with marked differences in the timing of onset, preparation and supervision of these roles. Despite these differences, the mothers narrated similar experiences of shock, fear and confusion in coping with their sick newborn, exacerbated by inadequate communication and information sharing between staff and mothers and a lack of psychosocial support.

The inequities in care observed in the Nairobi newborn units are barely visible in the mothers' own stories, instead they narrate a shared experience of their encounters with a biomedical model of care delivery. Advocacy for structural changes to reduce inequities in neonatal care are necessary. However, focusing on technological improvements risks further embedding a biomedical paradigm that ignores the needs of mothers.

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Finally, I wish to sincerely thank my family for always checking on me and being my source of energy.

## **Dedication**

I dedicate this thesis to my late parents George and Petronilla Oluoch and my entire family. The Suleh's, whom I often I turned to for much needed social support, thank you Dorothy, Audrey, Gerald, Andrew and Eve for the regular phone calls and reflection hours which always kept me going. To my sister Winnie for the encouragement and support during my UK visits. To my brother Alfred, knowing that you were also pursuing the same journey, also encouraged me. The phone calls from you towards the end asking me how it is going, are you done with the revisions? You all had my back! *Asanteni sana!*

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## List of Abbreviations

AAP	American Academy of Paediatrics
COPE	Creating Opportunities for Parent Empowerment
CMA	Critical medical anthropology
EBCD	Experience-based co-design
FCC	Family-centred care
HSDN	Health Services that Deliver for Newborns
HICs	High Income setting
IOM	Institute of Medicine
IPFCC	Institute for Patient and Family Centred Care
KDHS	Kenya Demographic and Health Survey
KEMRI	Kenya Medical Research Institute
KMC	Kangaroo mother care
KNH	Kenyatta National Hospital
KWTRP	KEMRI-Wellcome Trust Research Programme
LMICs	low and middle income countries
MCHB	Maternal and Child Health Bureau
MDGs	Millennium Development Goals
MNCH	Maternal, Newborn and Child Health
MCHIP	Maternal and Child Health Integrated Program
NBU	Newborn Unit
NNS	Nairobi Newborn Study
NHIF	National Hospital Insurance Fund
NG/t	Nasogastric tube feeding
NICU	Neonatal Intensive Care Units
OSOP	One sheet of paper
UK	United Kingdom
USA	United States of America
sSA	sub-Saharan Africa
SGDs	Sustainable Development Goals
WHO	World Health Organisation

# **1. INTRODUCTION AND OVERVIEW OF THE THESIS**

## **1.1 Burden of neonatal mortality**

Making progress in reducing neonatal mortality in low and middle-income countries (LMICs) has been slow (Lawn et al., 2014). In 2013, 6.3 million children died before 5 years of age. Of these, 44% (2.76 million) died in the neonatal period (Liu et al., 2015). The majority of the 2.76 million deaths that occur among neonates each year happen in LMICs (Oestergaard et al., 2011). Many countries in sub-Saharan Africa, including Kenya, fell short of the MDG4 target of reducing under-five mortality by two thirds by 2015, in large part due to a lack of progress in combating neonatal mortality (Bhutta et al., 2014; Lawn et al., 2014). Reducing newborn mortality is now a global priority (Gates & Binagwaho, 2014). The sustainable development goal 3 (SDG 3) covers neonatal and child mortality and has set the following targets to be reached by 2030: preventable deaths of newborns and children under 5 years of age will end; there will be a reduction in neonatal mortality to at least as low as 12 per 1,000 live births; and under 5 mortality will be reduced to at least as low as 25 per 1,000 live births (Sachs, 2012). Kenya has an estimated under-five mortality of 52/1000, an infant mortality rate of 39/1000 live births and a neonatal mortality rate of 22/1000 (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2014)

Improving quality and access to care for sick newborns is central to reducing this burden (Bhutta et al., 2014; Cuervo, 2013). A key step towards achieving this goal in high burden countries is improving the quality of care for hospitalized sick newborns (Bhutta et al., 2014). While ensuring effective clinical management is vital to the survival of sick newborns, a growing body of research has shown that social factors and caregiving processes are also important in shaping neonatal health outcomes (Davis, Edwards, Mohay, & Wollin, 2003; K. Johnson, 2013). For well newborns, most of these care processes are undertaken by the mother. But for hospitalized sick newborns much of this care is handed over to nurses and other health professionals.

## **1.2 Importance of parental involvement**

Having a child admitted to a hospital newborn unit (NBU) is a stressful event for a parent, often mixed with fear, grief, and uncertainty (Lee & O'Brien, 2014; Russell et al., 2014; Sisson, Jones, Williams, & Lachanudis, 2015). Mothers whose babies are born premature or sick may experience feelings of ambivalence, shame, guilt, and failure that are related to social prejudice (Obeidat, Bond, & Callister, 2009). Furthermore, admission to a newborn unit disrupts the maternal-infant bonding and attachment process, an important factor in infant development and maternal wellbeing (Young, 2013) as well a potential precursor to the consolidation of parenting skills, and future emotional, developmental and social milestones (K. Johnson, 2013). A recently published review of the literature on maternal-infant bonding reported that mothers who participated in immediate skin-to-skin contact and initiated breastfeeding within two hours following childbirth were more sensitive to the infant's needs and the child seemed more content at one year; while poor interaction affects the child's cognitive and socio-emotional development, physical health and personal relationships (K. Johnson, 2013).

A series of recent studies investigating the process of parenting in neonatal units found that involving parents in care can help in avoiding poor outcomes and reduced stress among parents (Alves, Amorim, Fraga, Barros, & Silva, 2014; O'Brien & Lynch, 2011; Russell et al., 2014). There is also increasing evidence that maternally delivered interventions such as emollient therapy (Salam, Darmstadt, & Bhutta, 2015), kangaroo mother care (Chiu & Anderson, 2009; Conde-Agudelo & Diaz-Rossello, 2016; Feldman & Eidelman, 2003) and preterm infant massage (Field, Diego, & Hernandez-Reif, 2010) have positive effects on the survival and long term development of low birth weight and premature neonates (Chiu & Anderson, 2009; Conde-Agudelo & Diaz-Rossello, 2016; Feldman & Eidelman, 2003; Salam et al., 2015). Involving parents in newborn care has the potential not only to enhance parenting skills but also to improve their perceptions of the care their child receives. Perceptions of the appropriateness of care is central to encouraging uptake of services, increasing compliance and potentially enhancing recovery and later development outcomes (Groene, 2011; S. Ziebland, Coulter, A., Calabrese, J., & Locock, L. (Eds.), 2013).

### **1.3 Strategy for parental involvement in the care of hospitalised newborns**

In high-income settings such as the UK, the USA, and Australia, parents and other family members have for many years played an important role in caring for hospitalized children, infants, and most recently, newborns (Franco, Bouma, & Bronswijk, 2014). Family-centered care (FCC) is based on a holistic paradigm of care that pays attention to the social and emotional wellbeing of a patient and the benefits of incorporating families in the care of patients (Jolley & Shields, 2009).

While family-centered care is a well-established paradigm in countries such as the UK, using the experiences of patients and caregivers to directly inform the provision of clinical care is an emerging field of increasing importance in these settings (S. Ziebland, Coulter, A., Calabrese, J., & Locock, L. (Eds.), 2013). For example, studies on patient experiences have led to changes in care provision in British general practice with a great focus being placed on communication between doctors and patients (S. Ziebland, Coulter, A., Calabrese, J., & Locock, L. (Eds.), 2013). Inclusion of patients' views and paying attention to their concerns has led to the development in high-income countries (HICs) of a strategy called Experience Based Co-design (EBCD) where patients and staff work together to improve quality (Bate & Robert, 2006). This strategy has contributed greatly to the redesign of healthcare in countries such as the UK (Brady, Goodrich, & Roe, 2019).

In the UK, the Experienced Based Co-design (EBCD) approach has been applied in services such as inpatient units, intensive care, mental health, surgical units amongst other services (PointofCareFoundation, 2018). The experiences of patients and staff are collected using methods that include in-depth interviews, observations and group discussions (Bate & Robert, 2006; PointofCareFoundation, 2018). Recently, Locock and colleagues in the UK evaluated different approaches to co-design and found that the use of video clips of local and national narratives of patients is effective, acceptable to staff and patients and that they triggered discussions between patients and staff about approaches to improve care (Locock et al., 2014). To date, this approach has primarily been adopted in the management of chronic conditions but a recent study of experiences of parents with infants admitted to hospital for surgery in the UK suggests that the methodology might be equally valuable in informing the provision of clinical care to sick infants (Hinton Lisa, Locock Louise, Anna-May Long, & Marian, 2018).

A family-centred care approach is embedded in the provision of sick newborn care in many high-income settings and evidence suggests that increasing attention is being paid to how

parents' experiences can be used to help inform the provision of care for this particularly vulnerable group. However, while the burden of neonatal morbidity and mortality lies within LMICs, little is known about the needs and involvement in care of families of hospitalized sick newborns in these contexts. Descriptions of approaches to care delivery for hospitalized neonates in LMICs are scarce and the impact on mothers of having a hospitalized sick newborn is poorly understood. Appreciating the role of mothers as part of a caring team for sick newborns in neonatal units, not just as the recipients of professional services, and designing strategies to use their health experiences to improve care quality could contribute to improving sick newborn health outcomes, particularly in low-income settings.

#### **1.4 Justification for the study**

Low and middle-income countries including Kenya, bear the greatest burden of newborn mortality and morbidity with health systems challenges such as poor staffing and training and lack of equipment compromising the quality of newborn care (Moxon et al., 2015). Little is known about the experiences of mothers with hospitalized sick newborns in Kenya and few data are available on their role in the provision of care for their babies. In high-income settings, involving families in sick newborn care has been shown to provide measurable benefits both for the baby and the mother, but the relevance and feasibility of this approach in Kenya and other low-income settings is unclear. Appreciating the perceptions and roles of the mothers of hospitalized sick newborns, and understanding the contexts which shape these experiences, is a first step towards assessing the relevance and feasibility of a family-centered approach to hospitalized newborn care in Kenya and other LMICs. Understanding what mothers feel, the roles they undertake and the coping mechanisms they employ is central to developing strategies that tap into the voices of mothers of hospitalized sick newborns. Incorporating such experiences has the potential to enhance the overall care provided to sick newborns during hospitalization and potentially post-discharge. Findings from this study will contribute to a growing body of knowledge on the care of hospitalized sick newborns in LMIC settings; an understanding of the feasibility of implementing FCC in such settings; and the potential for incorporating the experiences of mothers into the provision of clinical care in Kenya.

## **1.5 Research objectives**

This thesis is a first step in describing the experiences, roles and perceptions of mothers of hospitalized sick newborns and their interactions with health professionals in the neonatal units of two Nairobi hospitals; exploring mothers' roles, their experiences and coping mechanisms and critically assessing the context within which care is provided.

The overall aim of this research project is to understand the context of inpatient newborn care, roles, experiences and perceptions of mothers in the provision of care for sick newborns in two hospitals in Nairobi County, Kenya; and explore the implications of their experiences and perspectives for family centred care quality improvement strategies. The specific objectives of this research project are to:

- a) Describe the context within which sick newborn care is provided in two hospitals in Nairobi, Kenya
- b) Explore the practices and roles of mothers in the day to day care of hospitalized sick newborns in the two study hospitals.
- c) Examine the relationships among mothers and between mothers and nurses providing care in the newborn unit.
- d) Elicit the experiences and perceptions of mothers regarding their role and their involvement in the care that their hospitalized sick newborns receive.
- e) Critically analyse how the mothers' experiences align with the principles of FCC and reflect on implications for improving neonatal care.

My motivation to take on this study was premised on my previous research work and research interest on maternal and child health. In the year 2011, I joined the KEMRI-Wellcome Trust research program to undertake a qualitative study exploring perceptions surrounding the introduction of routine ultrasound scanning in Kilifi County Hospital, the main hospital in Kilifi County, in rural coastal Kenya. While working in this project, I was part of a multi-disciplinary team that was interested in perinatal and maternal health studies. While attending research meetings and engaging in discussions with my colleagues, I became more aware of some of the clinical and epidemiological issues surrounding Maternal, Newborn and Child Health. During this time, I also interacted a lot with other doctors and nurses working in the antenatal and maternity departments of the hospital. Spending a lot of time in these departments also meant that I spent a considerable amount of time interacting with mothers who were seeking care in the hospital. After the completion of this project, I moved on to develop and conduct an ethnographic study looking at the



continuum of care for maternal and newborn health, this time with a focus on looking at what was happening in the periphery communities and dispensaries in rural Kilifi County. Through conducting observations in these periphery facilities and shadowing nurses as they cared for these women in mainly three facilities (Junju dispensary, Maadamani dispensary, and Ganze sub-county hospital) I also got to meet other women of reproductive age who resided in these surrounding rural communities. In that study, I was able to interview several women, visited them in their homes, talked at length with them and their household members on matters relating to women's and children's health and their pathways to care. Listening to their stories and accompanying them for their antenatal visits, deliveries and postnatal care, raised my awareness of the challenges that these women faced with regards to accessing antenatal and delivery services. Some of these women talked about their past pregnancy experiences, delivery experiences, and outcomes.

During the conduct of these two studies, my current director of studies and main supervisor Caroline and I spent a lot of time each week, holding meetings, brainstorming and talking about some of the issues from the field. I also shared with her some of the issues which I observed in the hospital's maternity and delivery wards. I remember clearly, that it was during one of these meetings that the idea to develop a proposal around experiences of mothers of babies born sick or hospitalized at birth emerged, based on my observations in these hospitals and interactions with the women. At the same time, a group within the KWTRP based in Nairobi and led by Prof Mike English was developing a project investigating the state of neonatal care provision in hospitals in Nairobi, County (the Health Services that Deliver – Newborns (HSD-N) study). In discussions with the Nairobi group and with the support of Caroline and Mike I developed a proposal for a project to explore the experiences of some of the mothers whose babies were admitted to the HSD-N study hospitals. I submitted this proposal to the Wellcome Trust for a Research Training Fellowship which was funded. I then moved from Kilifi to Nairobi, and that was the starting point of this study.

## **1.6 Thesis structure**

This thesis has 8 chapters:

In Chapter One, I provide an introduction to the research topic and present the aims and objectives of this PhD. Chapter 2 provides a review of the literature on the main strategy being implemented at a global level of family-centred care as a strategy for providing holistic care that caters to the needs of parents as well as their sick children. I pay attention to the core principles of FCC highlighting why it is important. Chapter 3 describes Kenya's health

system with a focus on how care is organised in the country and a short description of the HSD-N, the project which this study was nested in. I draw on published literature, reports and policy documents. In Chapter 4, I present the study methodology. Here I present the methods as well as the conceptual framework that informed the selected data collection methods as well as the approaches for data collection. In this chapter, I also present my reflections on my positionality and role in the conduct of this research. Chapters 5, 6 and 7 are the results from the study, where I bring to the fore the key themes that emerged from this study.

In Chapter 5, I draw on my ethnographic observations to describe the two hospitals. I describe the context, staffing and organization of care as well as the practical norms of care. I also illustrate the differences between the two hospitals. In Chapter 6, I use my observations, informal conversations and discharge interviews to describe the tasks and the roles that the mothers undertake in the NBU in the two study hospitals while their babies are admitted. I also describe how the mothers are introduced into these tasks illustrating the timing, source of support and the concerns that they have performing the expected tasks. I introduce concepts of relationships that exist in the NBU between the mothers and between the mothers and the staff. In Chapter 7, I draw primarily on the post-discharge narratives to describe the experiences of the mothers and their emotional journey right from the birth of their baby, admission, progress in the NBU and eventual discharge home. Here I focus on the fears, tensions, concerns, and uncertainties that these mothers deal with on a day to day basis. I also describe how these mothers cope with these fears and uncertainties. In Chapter 8, I provide a summary of the study findings, present a revised conceptual framework. I provide a comparison across the two study hospitals as well as with existing literature from other settings. I further highlight the strengths and limitations of this study and provide suggestions or recommendations for quality improvement strategies in light of what the findings mean and how they might inform the incorporation of mothers' needs and voices in the NBU.

## 2. LITERATURE REVIEW

### 2.1 Approaches to healthcare

Since the early 20<sup>th</sup> century the biomedical model of health care provision has become globally dominant among the organised healing professions (Porter, 1980) but within this dominant biomedical model, health care practices are guided by paradigms which shift over time. Franco and colleagues in their 2014 review of health care paradigms define them as “*coherent constellation of beliefs, habits, and procedures for achieving certain goals in society*”(Franco et al., 2014). They make an assertion that paradigms are based on habits and traditions which are anchored in written and unwritten rules, in institutes, companies, and other vested interests. The biomedical paradigm is based on concepts of mind-body dualism where ‘mental health’ and ‘physical health’ are usually treated as separate issues and in which there is a focus on ‘diseases’ that can be identified and the underlying biological defect treated (Franco et al., 2014). However, despite the success of the biomedical model in controlling infectious diseases and contributing to increasing life expectancy in HICs, by the late 20<sup>th</sup> century in HICs the model was undergoing a paradigm shift as a result of the changing pattern of diseases, the increasing recognition of the need to take account of both provider and patient behaviours and the increasing cost of health care (Franco et al., 2014). As explained by Franco and colleagues, this shift involved a move towards a ‘biopsychosocial’ model (Engel, 1977) and the rise of the paradigms of care that take account of the social psychological and behavioural dimensions of health and illness (Franco et al., 2014).

The shift in focus from the biomedical model to a more biopsychosocial approach has generally involved a move from medical hegemony- “*the process by which the assumptions, concepts, and values of ruling classes or power come to permeate medical diagnosis and treatment*” (Csordas, 1988), towards more holistic models of care that places emphasis on the social and psychological wellbeing of patients and takes account of provider and patient behaviours (Franco et al., 2014). One of the current concepts of care of importance to this study is family-centred care. This concept of care recognizes the importance of emotional, social and developmental support to the care of patients.

## **2.2 Family-Centred care as an approach to paediatric care**

The history of hospitals caring exclusively for children can be dated back to the 1800s, a time when the role of a parent was said to be that of “visitors” or “attendants” (Jolley & Shields, 2009). In the mid-twentieth century, alongside the general rise in the concept of biopsychosocial models of care, there was increased recognition of the trauma in an inpatient setting of the separation between a child and their family. Between the 1920s and 1970s, literature from the UK and the US saw a growing recognition of the important role that families play in ensuring the health and wellbeing of hospitalized children (Jolley & Shields, 2009). The acknowledgment that emotional, social and developmental support are integral components of health care (Gooding et al., 2011) led to a change in hospital policies to allow for rooming-in, open visiting hours, sibling visits, and accompanying children to surgeries (Irlam, 2002; Jolley & Shields, 2009). In their paper exploring the history of family-centred care (FCC) Jolley and Shields (Jolley & Shields, 2009), highlight some of the key events that took place in the US and UK from 1955 onwards that led to FCC. These are summarized in table 2.1.

In the 1950s, in both US and the UK parents’ groups were at the forefront in calling for the improvement of care for their hospitalised children. These parents’ groups advocated for “child-friendly” hospitals and for parents to be given more access to their children in hospital as with hospitalization, such children were separated from their families and children faced long lonely hospital stays, visiting hours were short or even non-existent as a way of infection prevention. In the UK the Platt report which originated from such activism was the first to be implemented. Mother care of children in hospital was one such parents’ groups that brought parents and professionals together to advocate for the inclusion of parents in the care of their children. The Lobby groups were made up of health professionals as well as parents continued to later emerge in the 1960s across the US, UK and Australia and continued to advocate for the inclusion of families in the care of children (Jolley & Shields, 2009).

Table 2. 1 Emergence of FCC in the US and the UK

<i>Year</i>	<i>Who/where</i>	<i>Action</i>
1955	The Citizens Committee on Children of New York City	Advocated for more child-friendly hospitals that allow parents more access to their children
1959	British government	Publishing of the Platt report, an inquiry into conditions in the children's hospital.
1961	In Britain, the formation of Mother care of children in hospital (now Action for sick children),	A consumer organization formed by parents that supported the Platt report.
1962	Mother care of children in hospital formed in the UK	Survey to determine the level of parental involvement in British hospitals. Able to influence government as an electoral lobby group
1963 onwards	Lobby groups emerged in the UK and the US.	Advocacy and high influence over policy and development of children's health initiatives, in particular, those related to FCC.

*Source: Adapted from Jolley and shields, 2009*

In a recent publication, Celenza et al provided a historical context to the adoption of FCC in Vermont, USA. In this publication, they highlight the important role of work conducted in 1992 which brought together a group of parents and physicians to hold a dialogue about the participation of families of critically ill infants (Celenza, Zayack, Buus-Frank, & Horbar, 2017). Celenza and colleagues acknowledge that this interaction resulted in the proclamation of core principles of FCC in neonatal care that has continued to guide care in Vermont in subsequent decades. In this 2017 publication, the authors also present the efforts made by the Vermont network in involving families in quality improvement, these include:

- a) Through partnerships with the Institute for Patient and Family Centred Care (IPFCC), the Vermont network developed a self-assessment resource which was aimed at assessing family advisors' involvement in quality improvement strategies.
- b) Family advisors serve on quality improvement advisory boards.
- c) Efforts to measure the impact of the quality changes on families and exploration of co-design quality improvement projects.

FCC is an approach that was developed in the context of hospital care in high-income settings which emphasizes the partnership in the care and decision making regarding health

care between the family and health care providers (Kuo, Lee-Hsieh, & Wang, 2007; Salimi, Khodayarian, Bokaie, Antikchi, & Javadi, 2014; Vajravelu & Solomon, 2014). The Institute of Family Centred Care in the US defined FCC as “*an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial partnerships between health care professionals, patients, and families*” (Shields, Pratt, & Hunter, 2006). The underlying philosophy puts parents and the family at the centre of health care and promotes “*individualized, flexible care*” (Staniszewska et al., 2012). Shields and colleagues define FCC as a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients (Shields et al., 2006). It is defined by Mikkelsen, and Frederiksen as “the professional support of the child and the family through a process of involvement and participation, underpinned by empowerment and negotiation” (Mikkelsen & Frederiksen, 2011), while Griffin describes it as a philosophy of care for children that embraces a partnership between staff and families (Griffin, 2006).

Despite the varied definitions of FCC, there is consensus about its core principles postulated by various organizations such as the Family Voices in the US, the Maternal and Child Health Bureau (MCHB) in the US, the American Academy of Paediatrics (AAP), and the Institute for Patient- and Family-Centered Care in the US (Kuo. et al., 2012). The core concepts/principles of FCC highlighted in the literature include i) dignity and respect (ii) information sharing, (iii) participation, and (iv) collaboration. The first concept covers taking into consideration the perspectives and choices of the families by the health care providers. This also encompasses incorporating the families’ knowledge, values, beliefs and cultural backgrounds in the organization and provision of care. The second concept calls for health care providers to communicate and pass unbiased, timely, complete and accurate information to the families in a manner that is affirming and effectively promotes participation care and decision-making about their child. The third concept focusses on encouraging and supporting families to participate in care for their child and decision-making at the level they choose. Lastly, the fourth concept of FCC touches on the collaboration between healthcare providers, families’ leaders and patients in the: development of policies and programs, implementation and evaluation of programs, in healthcare facility design and in the delivery of care (Darbyshire, 1995; Kuo et al., 2007; Staniszewska et al., 2012). This increased family advocacy has, over time, seen the presence of family-centered care (FCC) become embedded at the highest policy level and its widespread adoption within clinical paediatric care in high-income countries such as the UK, US and Australia.

A recent scoping review of articles with an aim of exploring existing models of family-centred care in order to determine the key components of existing models and to identify gaps in the literature by Kokorelias and colleagues acknowledges that FCC models were developed for paediatric populations but over time other models targeted at adult populations such as patient-centred care have been developed. In their review, they identified core components of family-centered care models, the majority of which they argue are universal across different illness populations, ages or care contexts. As a result, Kokorelias and colleagues argue that the FCC models are applicable across diverse health conditions and experiences (Kokorelias, Gignac, Naglie, & Cameron, 2019).

### **2.3 FCC in neonatal care: involvement of mothers in care provision**

Over the past decades, the FCC approach has become a broadly accepted concept within paediatric intensive care in high-income countries and is becoming increasingly recognized internationally as important to neonatal care although its implementation in neonatology has been variable, with different models and approaches being implemented and undertaken by different NBUs, while some may focus of communication others may emphasize support of parents with tasks such as feeding, (Salimi et al., 2014). Where it is implemented, FCC in neonatal intensive care units (NICUs) allows for parental care and active participation of the parents (Wigert, Hellstrom, & Berg, 2008).

The FCC approach in neonatal care in high-income countries such as the UK, US, Sweden and Australia has most recently evolved into the promotion and practice of actively involving mothers in caring for hospitalised sick newborns (neonates) (Darbyshire, 1995; Hudon, Fortin, Haggerty, Lambert, & Poitras, 2011; Trajkovski, Schmied, Vickers, & Jackson, 2012). Some of the tasks that mothers perform in the NICUs in the UK for example with the help of a nurse include feeding, changing diapers, and bathing. Mothers are also encouraged to touch, read and tell stories to their newborns. For more stable babies in the UK, parents are encouraged to practice Kangaroo mother care (Darbyshire, 1995). In the UK, a 2014 qualitative study conducted across three hospitals with parents of preterm babies post-discharge found that parental involvement in caring for their babies in the NICU was encouraged and the tasks they undertook included washing, cleaning, nappy changing as well as being able to touch and hold the baby (Russell et al., 2014).

In Canada, a care-by-parent model has been implemented in 20 level 3 neonatal units, this family integrated care model is aimed at improving the quality, continuity, and consistency

of neonatal care and ensuring a smooth transition from hospital to home. This follows a pilot study of 31 infants and their mothers that the authors report to have positive outcomes for baby and mother; improved rate of weight gain among infants, an 80% increase in breastfeeding at discharge, and a 25% reduction in parental stress compared with retrospective controls. In this model, after orientation, parents are empowered to provide as much of their baby's care as they are able. Among the tasks that they undertake include, feeding, bathing, changing diapers, dressing, holding, skin-to-skin contact and administering oral medication. Parents also take part in education and they are encouraged to take part in decision making (Lee & O'Brien, 2014). Despite the positive reported outcomes, such interventions especially if implemented for the very critical babies could have certain barriers to implementation, some of which are highlighted in this study. The authors for example highlight challenges with rooming-in especially in resource-limited settings, they are also cognizant of the fact that parental involvement in the care of critically ill infants who may require advanced respiratory care or complex treatment may be a challenge as may further add to the distress amongst parents.

Parents who are given adequate information and encouraged to actively take part in the care of their neonates may gain a feeling of control of the situation thereby helping them to strengthen their parental identity (Wigert, Dellenmark Blom, & Bry, 2014; Wigert, Johansson, Berg, & Hellstrom, 2006). In a lifeworld interview study conducted with 18 families from a level III NICU in Sweden, Wigert and colleagues, 2014 found that for participating parents, adequate information aided them to deal better with the stress of their babies' admission. Parents in this qualitative study linked a lack of communication to feelings of loneliness and abandonment.

#### **2.4 Formal and informal structures supporting FCC implementation**

In addition to allowing parents to become involved in the day-to-day practice of caring for their baby while it is in the neonatal unit, several high-income countries such as in Sweden, Canada and the UK, have adopted a range of strategies that will support and actively encourage this involvement and enhance the practices of FCC. These include information and education, emotional support and counseling and economic support and compensation. Many studies have reported that communication between parents and NICU staff is an essential part of the support provided to parents. Good communication has been linked to reduced emotional stress as parents feel that they are taken notice of when the staff responds to their need for information (Kowalski, Leef, Mackley, Spear, & Paul, 2006; Kuo et al.,



2007; Turner, Chur-Hansen, & Winefield, 2014; Wigert, Dellenmark, & Bry, 2013).

More specifically, parents of infants admitted to neonatal intensive care units can be empowered through the provision of information and involvement in care to improve bonding, attachment, and caregiving skills. Herbst and Maree's study on parental empowerment depicts the need for being informed about the care that the child is receiving and the need for orientation and preparation of what to expect even before the infant is admitted (Herbst & Maree, 2006). Additionally, in the study conducted in the UK which was aimed at examining experiences of parental participation in the care of their hospitalised child on a surgical ward found that parents wanted to be introduced to the staff looking after their child. The parents who were provided with this support were more appreciative and exhibited less stress than those who were uninformed (I. T. Coyne, 1995). Parental participation has also been found to have positive effects on parental wellbeing. For example, in 2011 a national survey of parents whose babies had previously been admitted into NICU was carried out in the UK. This survey found that parents were largely positive about their involvement in their baby's care. The survey reported that 81% were involved as much as they wanted in the day-to-day care of their baby in tasks such as nappy changing and feeding. 77% of the respondents reported that they were encouraged to touch and comfort their newborn, with only 50% reporting that they definitely had as much "kangaroo care or skin to skin contact with their baby as they wanted (Howell & Graham, 2011).

In the US, an educational-behaviour intervention, Creating Opportunities for Parent Empowerment (COPE) has been developed to help parents of preterm infants cope with the stress of such deliveries (Melnik, Crean, Feinstein, & Fairbanks, 2008). From the first few days post-birth to nine months post-discharge, COPE teaches parents what to expect from their preterm infants. It also teaches parents how to identify the infant's characteristics, developmental cues, and milestones as well as how to interact with the baby in a manner that enhances development and growth. In this program, parents are provided with an audio CD, a booklet with developmental information, magnets that list 6 and 9 months development milestones paired with suggested parent activities to help stimulate infant development. A secondary analysis of data collected in 2006 from an RCT in New York to test the influence of COPE reported that it facilitates the development of critical parenting skills, reduced length of hospital stay, decreased hospital readmission, less stress and greater satisfaction with the NICU care, a higher level of confidence in their ability to care for the infant (Melnik et al., 2008). In the analysis, a Structural equation modeling was used to test the impact of the intervention.

In a few high-income countries formal support structures for parents of sick newborns extend beyond the immediate hospital setting. Sweden provides economic support or economic compensation to parents to cover loss of earnings, allowing them to stay in the hospital with their child (Wigert et al., 2008). In the UK, economic support for travel expenses, parking costs and vouchers for food in hospitals have been provided and emotional support and counseling services are also available (Field et al., 2010). The existence of such services have been reported through qualitative studies to contribute to positive experiences of parents whose baby had been admitted to a NICU in the UK (Field et al., 2010) and suggest that the governments in countries where these support services are provided, recognize that quality clinical care is not the only factor influencing positive outcomes for sick neonates.

## **2.5 Benefits and challenges of FCC**

Yu and Zhang (Yu & Zhang, 2019) conducted a systematic review and meta-analysis of RCTs in order to evaluate the effects of family-centred care on hospitalized preterm infants. The FCC models in the studies included introduction to the NICU environment; creation of opportunities for parents to participate in NICU care, such as feeding and decision making; and empowerment of parents to enter the NICU to visit their infants while the control group received the NICU standard care. Their analysis included four studies; two from the United States, one from Sweden and one from China. Two of the studies included in this review were conducted during NICU admission and the other two involved data collection both during admission as well as post-discharge. The main outcomes measured across these four studies were; total length of hospital stay including days from birth to hospital discharge, infant morbidity, feeding and growth, and neurobehavioural performance. The analysis found that there was a statistically significant difference in the total length of hospital stay between the FCC group and the control groups. The length of hospital stay was lower in all the FCC groups than in the control groups across all the included studies. Their analysis revealed that three of the four studies reported the effect of FCC on a range of morbidities; in one study there was reduced risk of moderate to severe bronchopulmonary dysplasia in the FCC group compared to control group in one study and no significant differences observed in other morbidities, two other studies did not report any significant differences observed in morbidities. Effect of feeding and growth was only assessed by one study which observed that babies in the FCC group achieved enteral feeding earlier as well as higher daily weight gain compared to the control group. This same study that reported an impact on feeding also reported an effect on neurobehavioral performance where they reported that

babies in the FCC group had a better tone and motor patterns and total performance compared to other babies in the control group.

Ramezani and colleagues also made similar conclusions. Ramezani and colleagues conducted a literature review of studies conducted between 1980 and 2012, through qualitative content analysis of the included studies, they found that that FCC and family participation has been associated with positive infant health outcomes, shorter length of hospital stay, fewer readmissions and enhanced breastfeeding (Ramezani, Hadian Shirazi, Sabet Sarvestani, & Moattari, 2014)

In their paper based on a review of studies, Gooding and colleagues explored the origins and advances in FCC in the NICU and identified various FCC delivery methods. They observed that several studies concluded that participation in infant care was linked to greater family satisfaction with the healthcare experiences; enhanced attachment between an infant and the family; improved long-term outcomes for mother and baby; and a positive impact on stress levels, comfort level and parenting confidence of NICU parents and families. Despite these reported positive outcomes, they caution that there are few large-scale randomized control studies to support most FCC practices or models of care (Gooding et al., 2011).

Qualitative studies involving small sample sizes report that FCC and parental involvement decreases anxiety and stress in parents resulting in their psychological wellbeing while for the staff it has been linked to the increase in their satisfaction (Herbst & Maree, 2006; Lee & O'Brien, 2014; Staniszewska et al., 2012). In a qualitative study conducted in South Africa, Herbst and Maree conducted 2 focus group discussions post-discharge with mothers whose babies had been admitted to the NICU. These discussions were aimed at eliciting the parents' needs and their views on empowerment. These findings were then shared with purposively selected neonatal nurses in a workshop to derive empowerment guidelines. Participating mothers identified quality of nursing care as key to their empowerment. For the mothers in this study, supportive and individualized care was important as it reduced their fears and stress. They also reported that it enhanced communication and trusting relationships between mothers and nurses within the NICU (Herbst & Maree, 2006). Despite these positive outcomes reported by such qualitative studies, as Gooding and colleagues point out, there is a need for additional evidence to support the reported impact of the implementation of FCC (Gooding et al., 2011).

Despite the positive effects of FCC cited in the literature of paediatric studies, other critiques of FCC exist, with two studies undertaken in the UK during the 1990s reporting parents becoming resentful because they felt that they were being “made” to do the nurses' work (Coyne, 1995; Darbyshire, 1995) (Coyne, 1995; Darbyshire, 1995). Using a semi-structured interview schedule administered to parents from a general paediatric surgical ward in south-east England, this study examined the reasons why parents chose to participate in the care of their hospitalized child providing a description of their experiences with participation (Coyne, 1995). This study observed that parents were reluctant to participate in tasks such as providing medication which they perceived to be a nurse's task. These concerns, therefore, do point to questions around its feasibility and consequences of its implementation.

More recently, studies have pointed to the gap between the concept of FCC and the challenges of implementation. In FCC within paediatric care, nurses retain primary responsibility for infants and supervise parents closely but a qualitative study in Sweden where staff and parents were interviewed to collect their views of health staff reported mixed views about the implementation of FCC. Some of the fears found in this study, particularly among nurses, were that parents might interfere with the equipment, or operate the machines in the absence of a nurse and that parents may not detect changes in their infant's condition that require prompt medical attention. There was also concern that parents may become more anxious about providing care for their sick infant (Wigert et al., 2008).

Other studies have found similar concerns with FCC and, in as much as the critical role that neonatal nurses play in the empowerment of parents is acknowledged, several studies have reported difficulties in its application attributed to a lack of clarity on how it should be implemented (Bruce & Ritchie, 1997; I. Coyne, 2008; Herbst & Maree, 2006). A qualitative study conducted in four paediatric wards in two hospitals in England found that although several nurses in the study reported they believe they involved parents and practiced FCC, they also had some doubts about how effectively it was being implemented (I. Coyne, 2008). Some of the factors interviewed nurses reported to be contributing to the difficulty in the implementation of FCC in Sweden for example include lack of knowledge, understanding, attitudes, lack of negotiation skills as well as poor communication (Wigert et al., 2013).

In addition, an underlying paradigm that continues to prioritize biomedical care and highly medicalized wards have been cited as a potential challenge to the effective implementation of FCC (Wigert et al., 2008). In a qualitative study conducted by Wigert and colleagues in

Sweden on the conditions of involvement of parents in neonatal care, it was observed that while nurses perceived that parents should be central in the delivery of care, in practice the nature of the care environment, that is dominated by machines, perpetuated the medicalization of care. For example, from their observations of the ward rounds, the authors noted that the discussions tended to focus on the medical status of the child, and little attention was paid to the family's social situation or even factors that might have affected the family's presence and participation in the care of the child. The authors argued that in FCC, nursing care includes a welcoming approach to the parents of sick children, however, the participation by parents in care delivery may not be considered by the nurses to have as high a priority as the medical technical aspects of the care. They observed that the ward rounds tended to focus more on the medical diagnosis, while the caring needs (which are more intangible) were disregarded (Wigert et al., 2008).

In addition, lack of attention to the needs of the mother and other family members, such as places to rest and sleep were also identified in this study as challenges to effective FCC. They observed that in such cases, mothers who have been discharged and still have neonates in the newborn unit (NBU) can be forced to sleep at home and return daily (Wigert et al., 2008). Nurses participating in interviewed have voiced concerns about their ability to effectively implement FCC and parents have found that their ability to participate can be constrained by the layout of the NICUs and the presence of medical-technical equipment (Mirlashari et al., 2019). The findings of the 2011 survey in the UK echoed some of these challenges, with 56% of the respondents reporting that they were not always offered overnight accommodation if they wanted to be close to their baby; 32 % of the respondents reporting a lack of space for their other children to play when visiting the unit; and a further 10% saying their children were not allowed to visit (Howell & Graham, 2011).

Gaining insight into the experiences of the parents of neonates admitted to NICUs and bringing to the fore aspects of care that are particularly important to parents has begun to play an increasingly important role in providing more personalized care for sick newborns that meet the needs of families (Russell et al., 2014). For example, as part of The Parents of Premature Babies Project: Your Needs (POPPY Project) in the UK, 55 interviews were conducted with parents of preterm babies about their experiences of care on the neonatal unit. The results contributed to the understanding of the needs and the things most valued by parents, which included; clear information; receiving emotional support; and practical guidance and encouragement in caring for their baby (Staniszewska et al., 2012). At the end

of the three-year project, resource materials were developed and sent to neonatal units throughout the UK to guide and inform the implementation of FCC.

These studies demonstrate that while in many high-income countries FCC appears to be well accepted as a concept, there are constraints to its effective implementation. There is a need for: continued negotiation and re-negotiation of roles between parents and staff; adequate training of staff; attention given to the voices of parents; and potentially a re-orientation of priorities from the provision of technology to the provision of care. A few recent studies have also highlighted the fact that the role of fathers in FCC is often neglected, with most studies on uptake and impact focusing on mothers' experiences (Herbst & Maree, 2006; Melnyk et al., 2008; Wigert et al., 2013). Understanding and addressing the needs of the fathers is potentially equally important since they are part of the family and key providers of care for both mother and baby in high-income settings.

The FCC approach was initially criticized for a lack of real evidence that it worked, or that it made a difference to outcomes for children and families (Irlam, 2002). Other critiques of FCC as an approach to care point to the fact that it is more focused on mother-infant bonding and attachment theory, thereby, potentially ignoring other key contextual factors that not only influence practices of care but also shape the kind of experiences that mothers of the hospitalised sick newborns have. Tallon and Snider criticize FCC for failing to keep in pace relevant theories such as systems theory which they argue are the most useful ways to analyse the complex interplay between the biological, psychological and social processes. They also take note of the lack of rigorous research-based evidence concerning the impact of FCC (Tallon, Kendall, & Snider, 2015). Additionally, it has been criticized for its lack of a universal definition (Jolley & Shields, 2009; Uniacke & Browne, 2018). Scholars such as Shields argue that this lack of common definition results in the differential implementation of FCC. Further, this has been linked to a lack of understanding and consensus among service providers as to what FCC interventions should look like or comprise of. Others have argued that this lack of unified definition has resulted in different variations of FCC interventions. The challenge with this as pointed out by critiques is that it then becomes difficult to effectively measure the impact of FCC approaches across all settings pointing to questions about its generalizability to LMICs, more so, as it is a concept developed in HICs (Tallon et al., 2015).

FCC has been described to be a relational dynamic (Shields, 2010), enactment and experiences of the four principles of FCC are linked to how nurses and patients, in this case,

relate with one another. Consideration of these relational dynamics is critical as it directly relates to the current debates around RMC particularly in LMICs. In her paper examining this concept of FCC, Shields draws our attention to some of the common themes reported by the studies across board which she says include “health professionals acting as gatekeepers for parents, ineffective communication between health professionals and parents, controlling parental access, unmet needs of parents and parents having to use various strategies to have those needs met” (Shields, 2016).

Considering these key issues raised above, it is apparent that we begin to critically think about contextually and culturally appropriate interventions that would best suit the LMIC settings which struggle with numerous health systems bottlenecks such as understaffing and inadequate infrastructure which could potentially impact on the implementation and uptake of interventions such as FCC. Since FCC is heavily reliant on both internal and external factors highlighted above, it is important to note that in settings such as Kenya, a one size fits all approach may not be appropriate as these may further introduce unintended consequences that may contribute further to health inequities. The challenges of implementing such an intervention must be kept in mind. As noted by Yu and Zhang, despite the many published reports regarding the benefits of FCC, there is a need for updated reviews and rigorous studies to measure the effects of family-centred care on preterm infants (Yu & Zhang, 2019).

## **2.6 In-patient delivery services, coverage, and need in LMICs**

Coverage of in-patient care packages and quality care are crucial to neonatal survival in both high and low-income contexts. What is known is that universal health coverage and quality neonatal care remain a challenge in LMIC settings (Moxon et al., 2015). Health worker shortages and poorly equipped facilities, lack of prioritization and underfunding, as well as a lack of specific knowledge and competencies in neonatal care pose a great challenge in the provision of high-quality neonatal care in LMICs (Dickson et al., 2014).

While little is known about if or how FCC is being implemented in the neonatal units in many LMICs, Herbst and Maree note that parents in LMICs are usually excluded from the decision-making process despite the known importance of parental involvement (Herbst & Maree, 2006). However, several studies have reported the involvement of families in providing non-clinical care for inpatients in hospitals (Alshahrani, Magarey, & Kitson, 2018; Islam et al., 2014; Zaman, 2004). Studies conducted in Kenya have reported the involvement

of families in the bedside care of patients in hospitals (Muthoni Maina, 2018; Nzinga, McKnight, Jepkosgei, & English, 2019). In a 2011 ethnographic study in Kenya of hospital domestics Hanna Brown vividly describes care in a typical public hospital (Brown, 2011). In these hospitals, she says that caregivers live alongside patients admitted to hospitals. The structure and design of the wards in this study are observed to bear striking resemblance to other hospitals in the East African region, the visual alignment Brown describes as aligned with institutionalized biomedicine, often characterized by technology, power differentials between the different cadres of staff as well as between the staff patients and their caregivers. This study also found that patient's conditions were rarely discussed with the families and rarely did families question the nurses or doctors. The involvement of families in the nursing of care of patients she found was allowed and practiced within the hospital. Her study depicts the hierarchical spaces in hospitals in this setting, different cadres of staff are allocated different spaces. Family participation she argues is made possible mainly because the nurses often felt overworked, and therefore to allow them time to concentrate on more clinical tasks, nurses allowed the families to take on the nursing tasks such as bathing patients, helping patients to use the toilet, feeding patients who could not eat by themselves, or turning bedridden patients.

Being derived from high-income settings, the FCC concept is based on the assumption that care is provided to sick children and neonates within a well-staffed and adequately functioning hospital context. By contrast, in much of sub-Saharan Africa (sSA), the majority of births take place at home without the presence of a skilled attendant, with wide disparities within countries across socio-economic status, geographic location and education status (Darmstadt et al., 2009). However, recent data indicate that the proportion of mothers accessing facility-based care has increased in many low- and middle-income countries (Wang, 2011). In addition, data show that increasingly in the urban African context, the majority of babies are being born in hospitals (Doctor, Nkhana-Salimu, & Abdulsalam-Anibilowo, 2018). For example, in Nairobi City County an estimated 89.4% of births take place within health facilities, compared to 42.6% on a national level. Newborn deaths account for 45% of all child deaths in Kenya (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2014). Nairobi County has the second-highest under-5 mortality rate in the country. Neonatal mortality is 39/1000 live births, higher than the national average which is estimated at 22/1000 live births (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2014). The overall incidence estimates of neonates requiring inpatient care in Nairobi City County was calculated to be 183.09/1000 live births (G. Murphy et al., 2018).



Despite the promotion of skilled delivery in health facilities as a means of tackling the MNC deaths, challenges leading to low utilization, particularly in LMICs are still reported in these settings (Bohren et al., 2014; Doctor et al., 2018). A key observed deterrent to the utilization of skilled delivery, especially amongst underprivileged women reported in studies, is the disrespectful and undignified care received in health facilities (Bohren et al., 2014). These practices, Bohren and colleagues assert, are a violation of human rights. Over recent years the mistreatment of mothers during childbirth in LMICs has gained a lot of attention, paving way to the growing number of studies examining how women are treated during childbirth (Molina, Patel, Scott, Schantz-Dunn, & Nour, 2016). Studies conducted in Kenya for example, assert that RMC is a key component of providing quality care (Ndwiga, Warren, Ritter, Sripad, & Abuya, 2017; Warren, Njue, Ndwiga, & Abuya, 2017). In their study on the mistreatment of women during childbirth in Kenya, Warren and colleagues reported negative experiences at childbirth. Women participating in their study reported a lack of confidentiality, lack of autonomy, abandonment by providers and dirty maternity units. The authors further argue that social and gender norms in communities, provider demotivation, poor management, a lack of equipment and supplies all contribute to poor treatment within health facilities in Kenya (Warren et al., 2017). These findings are similar to several studies conducted in other parts of Africa which also report disrespect, detention in hospitals, and other forms of physical and verbal abuse by women in health facilities (Ishola, Owolabi, & Filippi, 2017; Sando et al., 2016; Sharma, Penn-Kekana, Halder, & Filippi, 2019; Sheferaw et al., 2017).

Attempts to address these issues and improve maternal care have included the development of the concept of respectful maternity care (RMC) (Koblinsky et al., 2016). This concept shares some features with the core principles of FCC, particularly dignity and respect and information sharing. As defined by the WHO, RMC stands for:

*“care organized for and provided to all women in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labour and childbirth” (WHO, 2018a).*

As such, the WHO as a way of promoting positive childbirth experiences has provided recommendations for interventions that promote RMC, effective communication between staff and women in labour, companionship during labour and childbirth and continuity of care for positive childbirth experience (WHO, 2018b).

FCC cannot deliver on its promises unless greater understanding and support for FCC are achieved by health care providers. Additionally, the adoption of FCC in LMICs will require

an attitude change in the way clinical care is delivered (Herbst & Maree, 2006). With the changing socio-economic context in most African countries, slowly high and middle-income families in these countries are increasingly challenging the central care paradigm that for a long time clinicians have been unilaterally responsible for decision-making (Kuo. et al., 2012). Very little is known about how care is delivered in LMIC settings from the patients'/mothers' perspectives. Information from high-income contexts suggests that FCC helps improve neonatal and family outcomes, however, there is a gap in literature with regards to whether it is practiced and how it is practiced, the extent of mothers' involvement in neonatal care in LMICs settings. It is this gap that this thesis sets out to explore.

## **Summary**

In this chapter, I have provided an overview of the changes in the philosophies of care that guided the care of hospitalized sick newborns from the strict biomedical philosophies to FCC approaches. I have then introduced the FCC approach, describing its core principles and the benefits of such an approach to neonatal care for both mother and baby. I have then highlighted some of the challenges with the implementation of FCC globally and alluded to the space of the family in hospital care in Kenya. To date, RMC has focused more on prenatal and childbirth period and the concept of FCC has focused on paediatric and more recently in HICs also on neonatal care. The neonatal period, the focus of my study, falls between these two periods. Neonatal period has to a large extent been ignored and this is where most of the under-five mortalities occur. Based on the assumption that the FCC concept was primarily designed for paediatric care to look at the extent of families' involvement in the care of their hospitalised children, I am guided by the principles of FCC while keeping in mind and being aware that RMC might also have key contributions for this study.

### **3. CONTEXT OF MATERNAL AND NEONATAL CARE IN KENYA**

#### **3.1 Introduction**

In this chapter, I present the context of care in Kenya with a focus of describing how the Kenyan health system is structured, I then move on to discuss the policy and guidelines that shape maternal, neonatal and child health (MNCH), with a specific interest in examining their content in relation to FCC and patient-centered approaches to care. The objective of conducting this review of the policy documents and guidelines is to explore to what extent they speak to and support the participation of families in the care of hospitalised sick newborns. I also discuss where women give birth, followed by a description of the study setting where I present the burden of neonatal care in Nairobi. This chapter has four main sections:

- Section 3.2 provides an overview of Kenya's health system
- Section 3.3 provides the policy guidelines landscape of key government documents informing MNCH care provision in Kenya. I look at the extent to which these documents address the involvement of mothers and communities in the care of hospitalised sick newborns.
- Section 3.4 provides a description of the larger project in which this study was nested.
- Section 3.5 provides a discussion of where women give birth, introduces the study setting and burden of neonatal care in Nairobi.

#### **3.2 Description of the Kenyan health system**

Kenya has a pluralistic health system consisting of the private for-profit sector, the non-governmental organization sector (including faith-based organisations) and the government or public sector. Each sector provides care at a range of levels from rural health facilities through to tertiary. After the promulgation of a new constitution in 2010, Kenya adopted a devolved system of government, which came into effect in 2013. Devolution saw the creation of 47 counties, each of which is administered by semi-autonomous governments. The County governments which then became responsible for the health facilities under the County Ministry of Health. The roles and mandates of the National and county governments in relation to health are provided for under the fourth schedule of the Constitution: National government is mandated with health policy formulation, management of national referral

health facilities, capacity building and technical assistance to counties. The County government, on the other hand, is responsible for the management and staffing county health facilities and pharmacies, ambulance services and the promotion of primary healthcare. County governments are responsible for facilities classified under levels 1-5 (figure 3.1) (Nyikuri, Tsofa, Barasa, Okoth, & Molyneux, 2015)

Kenya's healthcare system is structured hierarchically. At the lowest level is the primary healthcare. Primary health care encompasses the community, and then graduates, with the referral of complicated cases from the community to higher levels of healthcare. Dispensaries and health centres are classified under primary care. The current structure consists of six levels (figure 3.1).

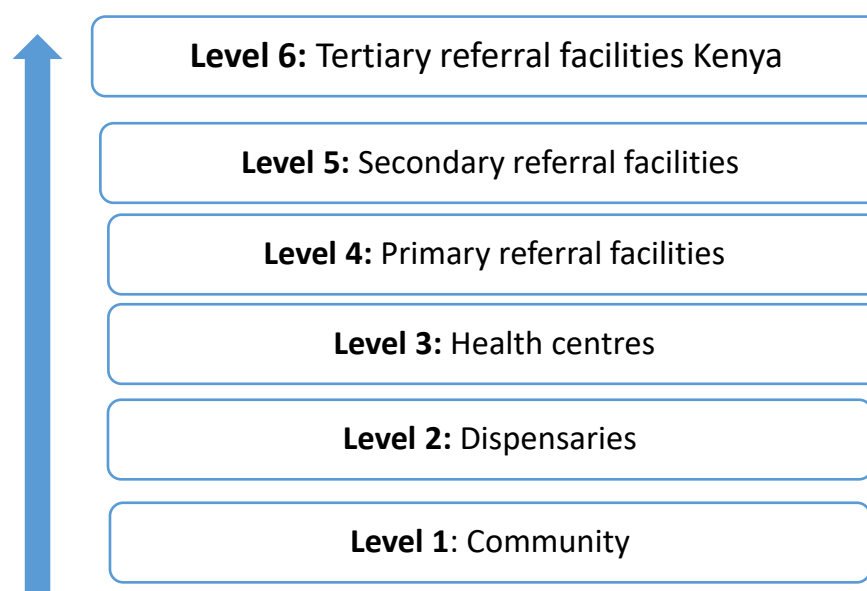


Figure 3. 1 Organisation of Kenya's health care system

(Source Kenya Health Policy 2014–2030)

### 3.3 Policy and guideline landscape; global and local context

Maternal, Newborn and Child Health (MNCH) remains one of the key priority areas for the Kenyan government. As a country, Kenya has aligned itself to global policies of importance to MNCH, these are the Millennium Development Goals (MDGs), Sustainable Development Goals (SGDs) (Sachs, 2012; WHO, 2017) and the Global Strategy for Women's, Children's and Adolescents' Health 2016-2030 (Kuruvilla et al., 2016). Among the key goals and

targets set in these global policy documents, is a reduction in maternal, newborn and child (MNC) mortalities and morbidities by all countries.

Apart from making an effort to achieve the targets set out by the above global strategies, the Kenyan government has also taken steps to encourage utilization and access to MNCH services in the country. In the year 2013, the president of Kenya made a declaration calling for free Maternity Services across all public hospitals in the country. The overall objective of the free maternity program was to increase access to skilled delivery services and hence the reduction of maternal and infant mortality (Tama et al., 2017). More recently, In October 2016, through the National Hospital Insurance Fund (NHIF), Kenya rolled out the Expanded Programme for free Maternity services- *Linda mama*-, whose aim is to achieve universal access to maternal and child health services. It covers one-year access to antenatal, delivery, postnatal care, complications during pregnancy, and outpatient care of the infant (NHIF, 2016).

Additionally, several policies, guidelines, and interventions have been developed and enacted in order to improve MNCH in the country. I summarize in *table 3.1* some key guidelines that guide neonatal clinical care in the country as well as key MNCH policy documents in *table 3.2*. Strengthening the capacities of individuals, families, and communities to improve maternal and newborn health is recognized in the National Road Map for Accelerating the attainment of the MDGs Related to Maternal and Newborn Health in Kenya (2010) (*table 3.2*). This document identifies 6 pillars of MNH in Kenya (*figure 3.2*), these are: pre-conceptual care and family planning, focused antenatal care, essential obstetric care, essential newborn care, targeted post-partum care and post-abortion care. Underpinning these services is skilled attendance and a supportive and functional health system. More importantly, the policy recognizes the potential role communities have in health promotion, although strategies for exactly how this should be done are not well represented in the document. The fourth and fifth pillars recognises the importance of strengthening the interface between the community and health services, as well as the human rights approach to health service delivery.

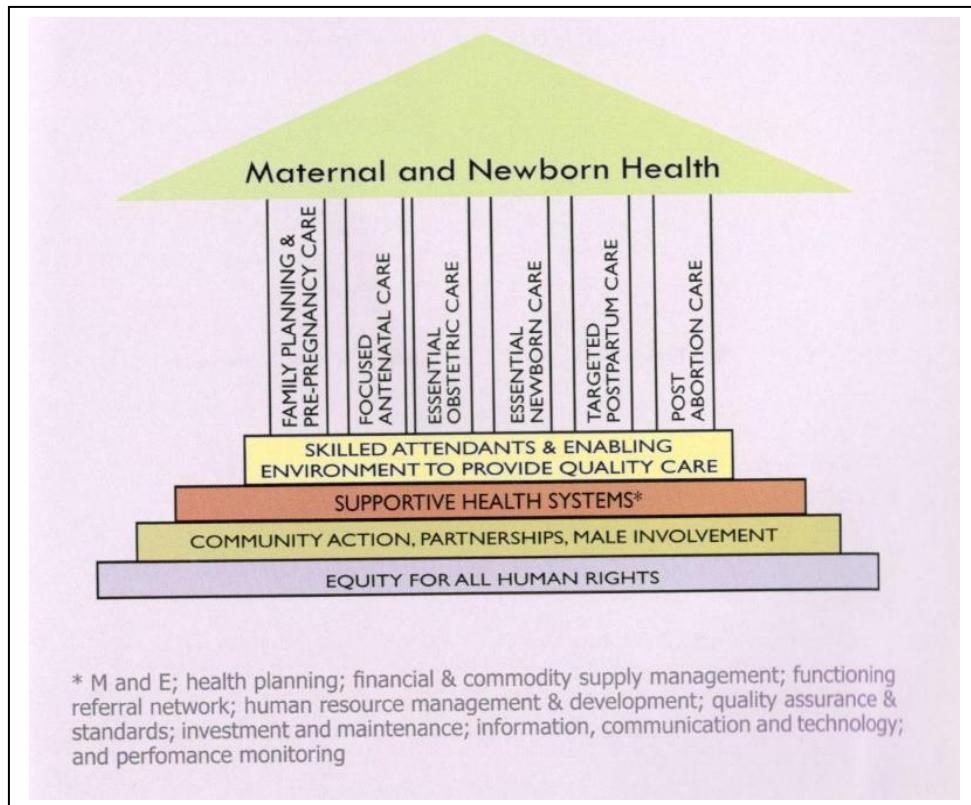


Figure 3. 2 Kenya Maternal and Newborn Health Model

Source: National Road Map for Accelerating the Attainment of the MDGs Related to Maternal Health and Newborn Health in Kenya (2010)

Table 3. 1 Summary of MNCH guidelines

<b>Document</b>	<b>Content</b>
Basic pediatric protocol for ages up to 5 years (2016)	Classification of illness severity. Criteria for admission. Inpatient management of the major causes of childhood mortality such as pneumonia, diarrhea, malaria, severe malnutrition, meningitis, HIV and neonatal conditions. Management of seriously ill newborn in the 24-48 hours.
National Guidelines on essential Newborn care (2015)	For use in training on evidence-based high impact interventions. Aimed at building the capacity of health workers on current newborn management protocols.
Malezi Bora: Afya ya leo ni uzima Kesho-Job Aids (2015)	Nutrition, growth monitoring and promotion, breastfeeding, vitamin A supplementation, management of the sick child, preventive activities and messages.
Integrated Community Case Management for sick Children under 5 Years- Participant's Manual (2013)	Treatment interventions in areas that experience access to challenges. Manual used in the training of Community Health Workers (CHWs)
Guidelines for the Prevention of Mother to Child Transmission (PMTCT) of HIV/AIDS in Kenya (2012)	Risk of mother to child transmission of HIV, Early initiation of ARV at 14 weeks- stresses the importance of early ANC attendance for all women. Information that programme managers need in order to make their facilities PMTCT friendly.
National guidelines for Quality Obstetrics and Perinatal care (2010)	Maternal health care knowledge, skills, and positive attitudes at all levels of service delivery
Baby-Friendly Community Initiative (2016)	Support for breastfeeding initiatives.
Kangaroo Mother Care Implementation Guide	Support for KMC

Table 3. 2 MNCH Policies in Kenya

<b>Document</b>
Newborn, child adolescent health (NCAH) policy (2018)  Overarching policy providing a holistic view and a unified approach to multiple programmatic (vertical programmes) and strategic documents. It provides direction on the coordination of the health responses for newborns, children, and adolescents.
Kenya Health Policy 2014-2030. Towards attaining the highest standard of health (2014)
National orientation package for targeted postnatal care (2011)
National Road Map for Accelerating the attainment of the MDGs Related to Maternal and Newborn Health in Kenya (2010)
National Strategy on Infant and Young Child Feeding 2007-2010.

*Source (MoH), 2019*

It is evident that several policy documents and guidelines on MNCH care exist in the country, however, none of them focus on FCC. The baby-friendly initiatives and KMC documents recognizes the importance of breastfeeding and skin-skin contact for the developmental outcomes of babies. Outlined in these documents are the areas of support and instructions for service providers on the support that should be offered to mothers. In Kenya, two maternally delivered interventions being promoted are 1. Exclusive breastfeeding for 6 months – the recommendation is that babies should start breastfeeding within two hours and mothers should be supported; and 2. Kangaroo Mother Care (KMC) of stable preterm babies. Kangaroo Mother Care is “the early, prolonged, and continuous skin-to-skin contact between the mother (or substitute) and her baby, both in hospital and after early discharge, with support for positioning and feeding” ((MCHIP), 2012).

### **3.4 The HSDN project**

The study was nested within a larger project called the Health Services that Delivers for Newborns (HSD-N). The HSD-N project conducted in Nairobi between 2014 and 2019 was a multidisciplinary project of work that aimed to establish the potential burden of severe neonatal illness in Nairobi County. The project also examined the existing infrastructure,



material and human resource capacity supporting access to neonatal care in Nairobi (Murphy et al., 2016). The project also looked into the utilisation of inpatient newborn services in Nairobi and a final stream of work explored the quality of existing services, as well as the important role nurses, play in providing quality care.

The health facility assessment conducted as part of the HSD-N studies within 31 hospitals in Nairobi that provide 24/7 care for sick newborn (across all sectors) observed that over 71% of all neonatal admissions in Nairobi were in the public sector. The public hospitals were also reported to bear the highest admissions levels and, high patient to nurse ratios of 7-15 per nurse and had higher mortality rates (G. A. V. Murphy et al., 2018). The nursing ethnography work as well as stakeholder analysis which were also part of the HSD-N project reported that understaffing and difficult work conditions within public hospitals in Nairobi led to informal task shifting of tasks within newborn units in Nairobi (Nzinga et al., 2019; Oluoch et al., 2018). Evidence from the HSD-N studies indicates that mothers of hospitalized sick newborns participate in caring for their babies (Nzinga et al., 2019), however not much is documented about the existence and incorporation of the core concepts of FCC.

### **3.5 Study setting**

This study was carried out in Nairobi County, the capital city of Kenya (figure 3.3). Although Kenya is making progress in reducing childhood mortality, less progress has so far been made in reducing deaths among newborns (0-28 days old). Compared to the rest of the country, data indicates that Nairobi has a considerably higher rate of hospital deliveries (88.7%) in comparison to 61.2% on a national level (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2014). Of these deliveries, approximately 59% happen in a public facility, 21% in a mission facility followed by 20% from private facilities (G. Murphy et al., 2018). According to a report by the African Population and Health Research Centre, over 60 % of Nairobi's population lives in slums. This report also highlights that the county exhibits high-income inequalities (APHRC, 2014).

The study setting has recently experienced serious health systems challenges as a result of health workers' industrial strikes. Towards the end of the year 2016 and much of 2017, Kenya faced major protracted health worker strikes that affected services across all public health facilities in Kenya. The first was a nationwide doctors' strike lasting 100 days (from 5 December 2016 to 14 March 2017) and then the nurses' strike lasting 150 days (from 5 June to 1 November 2017) (G. Irimu et al., 2018). Neonatal care in public hospitals in

Nairobi was therefore greatly affected during these periods. Expectant mothers and babies requiring hospital care turned to mission hospitals and other private hospitals for care during these periods of health worker strikes.

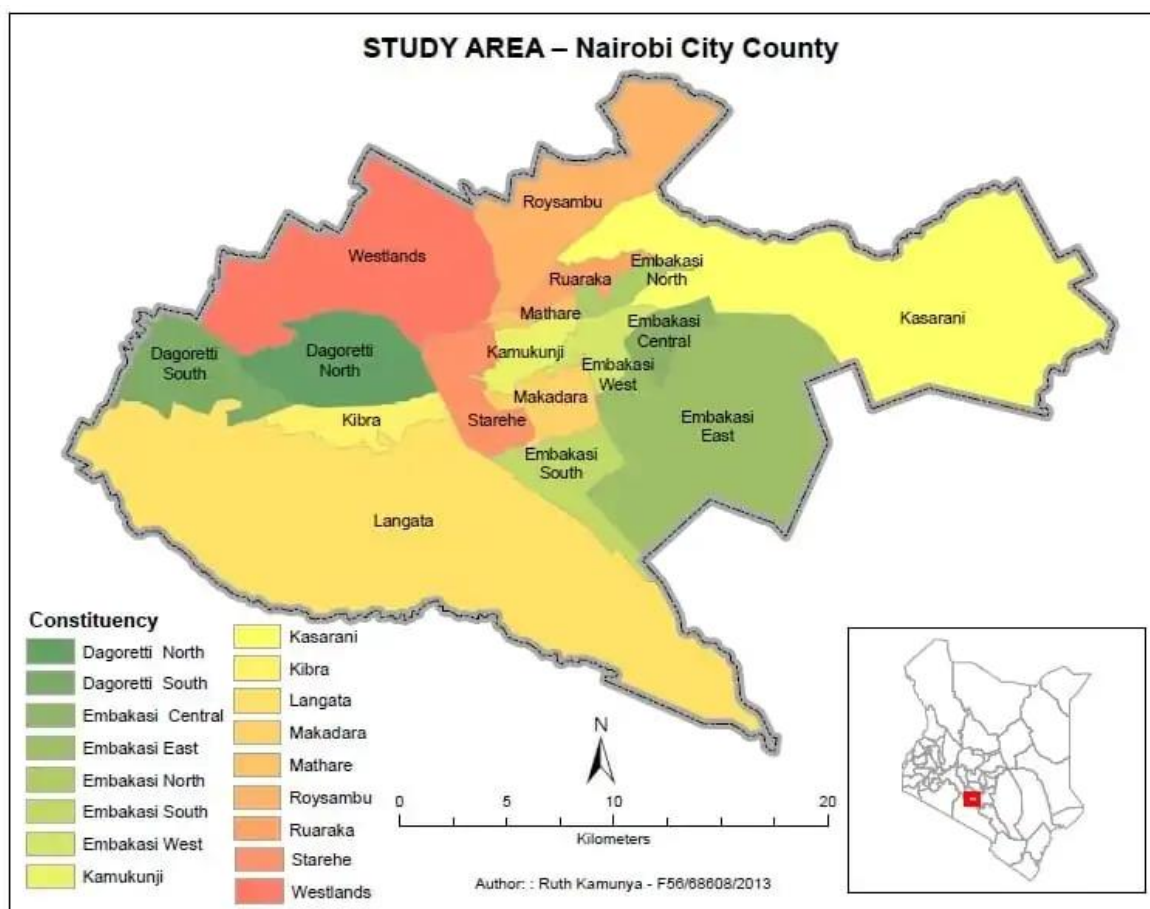


Figure 3. 3 map of Nairobi County

Source Google maps

### Chapter summary

In this chapter, I have provided an overview of the Kenyan health system and highlighted some of the key policy and guideline documents informing and guiding maternal and newborn care in the country. I have also introduced the study setting discussing where women give birth and the burden of neonatal care in Nairobi. I have also described the larger project within which this study was nested highlighting some of the key findings from the various components of this wider multidisciplinary project.

## **4. DESIGN AND METHODS**

### **4.1 Introduction**

In Chapter 3 I described the growing need for family-centered approaches to neonatal care and provided a summary of the policies and guidelines on maternal and neonatal health in Kenya. In this chapter, I now explain the conceptual framework and approach I followed in conducting this study. This chapter also describes the study design, data management processes, and analytical approach that I used. The last section of this chapter is my reflection on my positionality in this research.

### **4.2 Conceptual framework**

The outputs of the literature review conducted in chapter 2 focusing on the concepts of FCC, together with a theoretical approach derived from critical medical anthropology (CMA) informed the development of the conceptual framework that guided this research (figure 4.1).

CMA is a school of thought that emerged in the late 1970s and came to prominence during the 1980s as an approach to understanding how health inequities are shaped by social and economic structures and institutions that create, enforce and perpetuate observable disparities in health (Morsy, 1979). The approach emphasizes “the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (M. Singer & Baer, 1995). That is, its focus is on how the ‘sufferer’s experience’ is shaped by political, economic and social forces, not just disease pathologies. Leading scholars of CMA such as Soheir Morsy and Hans Baer (M. Singer & Baer, 1995; Merrill Singer & Baer, 2011) offer a critique of biomedical and anthropological ecological and interpretive approaches to health disparities arguing that such approaches fail to take into consideration the impact of macro-level factors i.e. political and economic forces on the micro-level health and illness experience. In addition, just as in medical anthropology, they argue the organisation and management of health systems in many high and low-income countries are dominated by biomedicine which is itself a cultural system with sets of beliefs, rituals and power relationships that deserve the same critical analysis as any other cultural system (Singer and Baer 1995).

The CMA approach has evolved over the years and in the 1990s the term ‘structural violence<sup>1</sup>’ was introduced into CMA theory to help highlight how macro-influences shape micro-level health outcomes (Farmer 1997; Scheper-Huges 1992). Farmer adopted the term to describe the inability of TB sufferers in Haiti to comply with treatment regimens; placing emphasis on their willingness to comply but describing how broader social, political and economic forces made it impossible for them to be able to comply with complex treatment regimens (Farmer 1997). Farmer has continued to apply this theory in his research on HIV/AIDS and more broadly, highlighting the connections between poverty and disparities in health care and outcomes (P. Farmer, 2003). Other authors who have adopted a CMA approach to health and used the term structural violence to describe inequities include Nancy Scheper-Hughes who used the term in her Brazilian study, examining mothering amidst everyday experiences of scarcity, sickness, and death (Nancy Scheper-Hughes, 1992). In this study she describes how mothers in this Brazilian village who live in these extreme conditions react to the sickness and death of their infants, thereby challenging the notions of ‘mother’s love’.

Using the CMA approach, I designed a conceptual framework that illustrates how the macro-structure of the social, political, cultural and economic context are important in shaping the philosophies of care and functional capacity of the health system, which in turn influences the paradigms of care and functional capacity of the study hospitals. The care paradigms are reflected in care structures (physical and organizational) of each hospital (Lassi, Middleton, Bhutta, & Crowther, 2016). These, together with the functional capacities of the hospital, influence caring in practice. In addition, the social, political, cultural and economic context shape community and family support mechanisms and the cultural norms of neonatal care which influence the micro-level practices of care of individual sick newborns (right-hand side of figure 4.1).

The study was undertaken using a CMA lens which requires recognition of macro-level factors influencing the micro-level health issues under investigation. The micro-level issue in my study was the ‘suffers experience’ - the individual experiences of mothers who had a sick newborn baby admitted as an inpatient in the study hospitals in Nairobi. That is, the focus for my data collection was the centre of the diagram (figure 4.1), the micro-level of practices of care within each newborn unit. To frame my analysis of these practices I drew

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<sup>1</sup> The term was first used by Johan Galtung in the 1960’s to describe how social structures, economic, political, religious and cultural factors situated at a macro level could potentially hinder individuals, groups, and societies from accomplishing their full potential or put them at risk of preventable suffering (Galtung, 1969).

on the literature to identify the common basic tenets of FCC. These I identified as (i) dignity and respect (ii) participation (iii) collaboration; and (iv) information sharing. My study was concerned with exploring the practices of care in the NBUs of the study hospitals and critically analyzing how these practices are shaped by broader macro-level influences as well as their alignment with the tenets of FCC.

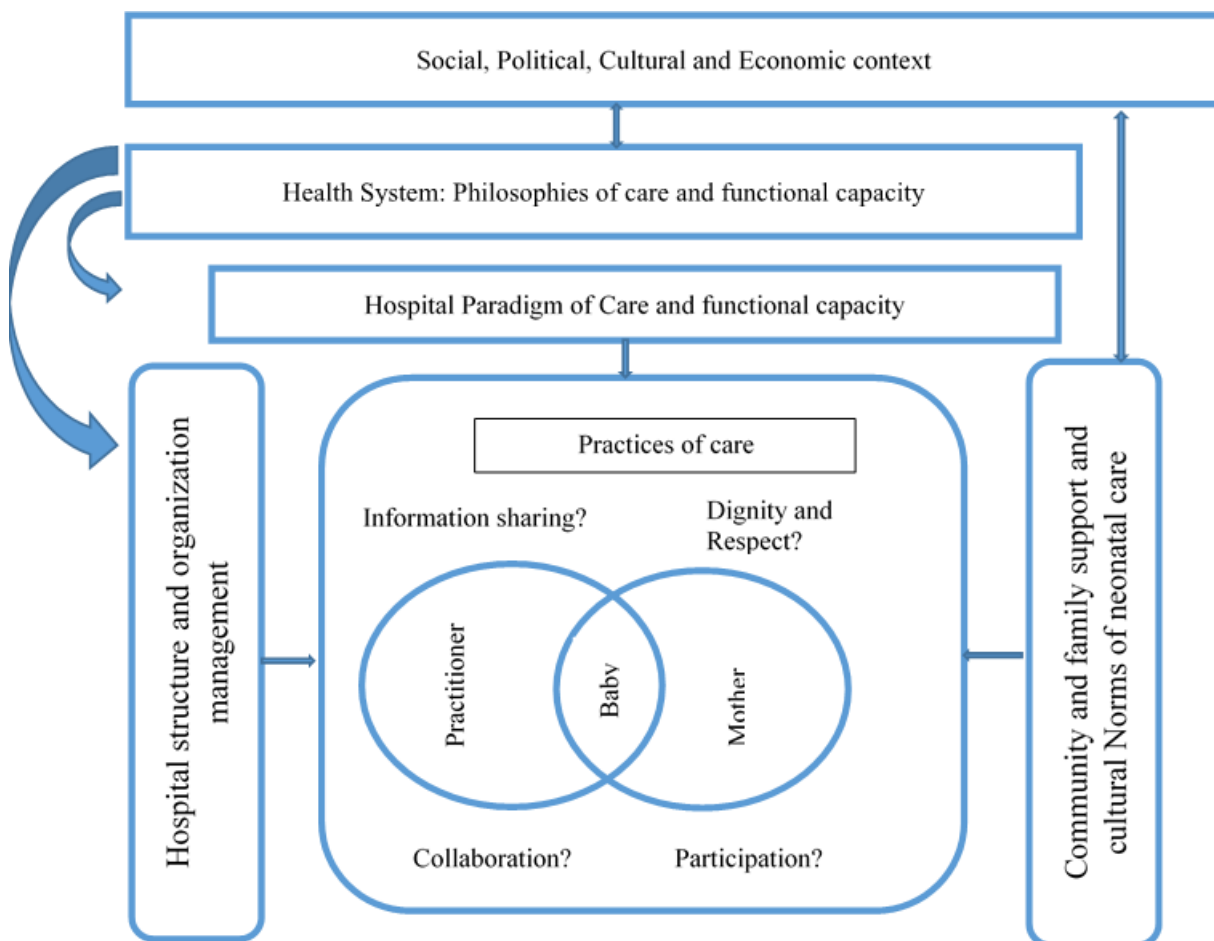


Figure 4. 1 conceptual framework

In addition to the CMA theoretical approach that guided the development of my conceptual framework and helped focus my analysis, in this analysis, I also drew on the works of Pierre Bourdieu particularly on his insights on forms of capital. In his theory of Capital, Pierre Bourdieu identifies three forms of capital of interest to my study, these are 1) Social capital, 2) Economic capital and 3) Cultural capital (Bourdieu, 1986). Social capital as explained by Bourdieu stands for social networks and social relationships that result in collective identities. He describes economic capital as money or assets owned by someone which gives them status in society. Lastly, cultural capital denotes what one has, and the knowledge possessed by an individual. Bourdieu further classifies cultural capital into; a) embodied-

which are the qualities of one's mind or body and this denotes the skills and mannerism that are possessed by an individual. People from higher social class differentiate themselves from others by how they look and behave. b) Institutionalized -which are linked to one's credentials or qualifications that may symbolize authority and c) Objectified-which are a person's material belongings, the kind of material items that one owns, depending on settings can be a symbol of status, prestige and power (Bourdieu, 1986). All these forms of capital determine one's social position in society. These forms of capital have been applied by researchers interested in understanding health inequities and in health research (Derose & Varda, 2009). Pinxten and Lievens applied these concepts of capital in their investigation of social inequalities in perceptions of mental and physical health in Belgium (Pinxten & Lievens, 2014).

### **4.3 Study design**

This was a descriptive research study using an ethnographic approach. As described by Creswell, an ethnography is a description and interpretation of a cultural or social group or system (Creswell, 1998). In studying health experiences, ethnographers immerse themselves in the settings in which these experiences take place (in this case the wards of Nairobi hospitals) for prolonged periods of fieldwork (Bernard, 2017). Adopting this approach enabled me and my research assistant to collect detailed descriptive data of the context of care within the two study hospitals. Through these extended long hours of observations, I was able to further form an understanding of the practices and culture of the study group (in these instances mothers of sick children in the context of a hospital ward). I paid close attention to the experiences and interpretations of the mothers. Ethnography allows for the collection of data using various methods, in my study I used three main methods of data collection, described in section 4.4.

#### **4.3.2 Sampling strategy**

Ethnographic studies aim for providing thick descriptions of the phenomena under investigation, with a small purposefully selected sample being studied intensively rather than extensive sampling to produce a random, statistical sample of the population (Fetterman, 1989). Since this study was conducted using an ethnographic approach the sampling for both the study hospitals and study participants was purposive. I chose to conduct the study in two study hospitals with a small sample of women.

This qualitative study was therefore conducted in two of the larger HSD-N hospitals. The two hospitals were:

- A public hospital, which I call Kijani; Built in the 1950s to offer health care services, mainly for infectious diseases. This hospital has a bed capacity of approximately 170. The majority of the users are drawn from the low-income area including the surrounding slum of Kibera. The hospital provides 24/7 neonatal care as well as a full range of general outpatient care services.
- A mission hospital that I call Tausi; It was established in the 1970s with the aim of providing affordable care. The preliminary data from the HSD-N study showed that women seeking maternity services in this facility come from across different locations of Nairobi. Nairobi West (36.8% of maternal patients), Kasarani (5.0%), Embakasi (4.6%), Umoja (4.6%), and Karen (3.9%). Two to three percent of admissions came from Kinoo, Kibera, Langata, Mugumoini, Kenyatta/golf course, Kikuyu, Kahawa, and Kawangware each.

The hospitals were purposively selected for providing inpatient neonatal care for 24 hours 7 days a week and cared for more than 100 babies annually. Initially, I had planned to carry out this study only in public hospitals. As presented in chapter 3, in Nairobi County, the majority of babies requiring 24/7 neonatal hospital care were being cared for in public hospitals. However, in the course of the second month of fieldwork, in June 2017, in the first public hospital, fieldwork was interrupted by the nurses' strike which lasted over 3 months. It was unclear when the strike would end, and thus following consultation with my supervisors, we made a decision to put in an amendment to the study protocol in order to include a mission hospital. At that time, another ethnographic study was going on in a mission hospital that had a comparable level of utilization to Kijani. Therefore, to avoid burdening that particular mission hospital, I made a pragmatic choice to conduct the study in Tausi.

For the mothers, I purposively selected mothers who gave birth in hospital and whose baby was immediately admitted to the sick newborn unit. Factors influencing which mothers were more closely followed and who were involved in the discharge interviews included: having a baby who was moved from acute care and into being cared for in the general sick newborn unit prior to discharge; and agreeing to participate in the study and providing informed

consent. Details of the recruitment process for the various methods of data collection are described in subsequent sections of this chapter.

#### 4.3.3 Recruitment of research assistant

I recruited a research assistant (TO) to help with the data collection, as the study was going to involve fieldwork in two study hospitals as well as home visits. At the time of joining the team, TO was in her final stages of her Master's course in public health. She had also been involved in two MNCH studies where she had conducted interviews with mothers seeking delivery services in Nairobi and western parts of Kenya.

### 4.4 Data collection methods

#### *Non-participant observation*

This methodology involves observing participants (*in my study with their knowledge*) but without actively participating in the activities (Spradley, 1980). My research assistant and I were not clinically trained and thus could not be able to fully participate in the activities of the newborn unit (Wind, 2008). Non-participant observation is used to understand a phenomenon by entering the community or social system involved while staying separate from the activities being observed (Fetterman, 1989). Alongside the observations, informal conversations took place with the mothers and nurses present in the sick newborn units during the course of the study. These day-to-day conversations were unstructured and enabled us to follow up on issues that we observed while in the NBU (Green & Thorogood, 2018). Secondly, as opposed to relying only on interviews, through observations researchers are able to collect data pertaining to what people do as well as what they say (Kiefer, 2006). However, its greatest limitation is that it is time-consuming and as observed by various researchers, people change their behaviour especially when they know that they are being observed, a phenomenon referred to as the Hawthorn effect. I was aware about this form of reactivity and thus emphasized the need for building rapport with the mothers while conducting observations in the newborn unit (Creswell, 1998; Green & Thorogood, 2018).

The nonparticipant observations focused particularly on the tasks and roles that the mothers played and the nature of the relationships that existed within the ward. We spent time observing the day-to-day occurrences and care provision in the ward, we wrote short notes during the day which we then expanded at the end of each day either in our field notebooks or typed out on MS word on our computers (Spradley, 1980). Occasionally I kept my own voice diary, where I recorded my personal thoughts and reflections. During these



observations, we identified mothers whose babies were becoming stable and were likely to be moved onto the less intensive newborn units prior to potential subsequent discharge (within a week or two).

### *Discharge in-depth interviews*

The second method of data collection involved formal semi-structured in-depth interviews with mothers at the time of their baby's discharge from the hospital. Fetterman describes interviews as "the ethnographer's most important data gathering technique as they explain and put into a larger context what the ethnographer sees and experiences" (Fetterman, 1989). We interviewed 20 mothers from each of the two study hospitals. As alluded to above, this methodology in essence thus allowed me to confirm and follow up on our observations. The interview elicited information on the mother's roles, perceptions and experiences during her baby's hospitalization. I used a topic guide to guide these interviews (Appendix B). We asked open-ended questions that were followed up by probes to elicit additional information. Although this is an important method applied in health research, the key limitations of this methodology is that it could potentially generate data relating to what people say, and not necessarily what they actually do. Furthermore, the sample size of people interviewed is in most cases are very small and thus the findings are not generalizable (Green & Thorogood, 2018).

### *Experience narratives/ storytelling*

A final method of data collection that I used was the collection of experience narratives. This method of data collection involves capturing people's involvement, understanding and feelings about events (in this case coping with their baby being born unwell and being hospitalized) in their own words through the stories they tell about their experiences (S. Ziebland, Coulter, A., Calabrese, J., & Locock, L. (Eds.), 2013). The approach allowed the mothers to share their personal narratives of coping with a sick newborn baby while in hospital and immediately post-discharge. During the discharge interviews, six mothers from each facility were asked their willingness to participate in this last activity. These mothers were purposefully selected on the basis of: ease of conducting house visits post-discharge; likely ability of the mother to narrate her story; and potential feasibility of gathering a coherent narrative. This involved visiting each of the mothers in their own homes around 3-6 weeks, after their baby had been discharged from the hospital, and asking her to tell the story of her experiences since the birth of their baby. Ziebland points out that as a method, narrative interviewing bears some ethical issues. She observes that since its unstructured nature makes it difficult for the researcher to have prior knowledge of the content of the

interview. Unlike with other methods, in narrative interviews, the content of the interview and follow up questions may not be clear beforehand to both the researcher and the participant. The story flows based on what the participant feels is important to him/her, it is heavily driven by the participant and there are no predetermined structured questions (S. Ziebland, Coulter, A., Calabrese, J., & Locock, L. (Eds.), 2013). Additionally, similar to other forms of qualitative interviews, it also involves a small number of participants and as such, it is not possible to generalize findings drawn from narrative interviews (Anderson & Kirkpatrick, 2016).

While discussing each method used, I have pointed to some of the strengths and limitations of each method. I have further alluded to how each method builds onto and strengthens the other. Gathering information through more than one method of data collection and from more than one standpoint over the period of a baby's hospitalization and immediate discharge allowed me to map out the social complexity of sick newborn care and provided a thick description of the perceptions and experiences of mothers whose babies were born sick and spent the first few days or weeks of their lives in hospital. Thick descriptions provide detailed accounts of field observations and experiences and as Geertz posits, this makes it possible for readers to evaluate the extent of transferability of the research findings (Geertz, 1973).

## **4.5 Process of data collection**

### **4.5.1 Pilot field work**

This was the first qualitative study on the experiences of mothers of hospitalised newborns to be conducted in Nairobi. I was therefore not certain of the acceptability and feasibility of some of the methods I was proposing to undertake in this study. I had initially planned to include a fourth data collection method in this study, the use of diaries by the mothers to record their experiences while their babies were in the hospital. In this method, a sub-sample of mothers were to be given the option of keeping either audio or written diaries of their daily experiences. To determine the feasibility of my data collection methods in this context, I decided to begin my fieldwork with a 1-3 weeks period of pilot data collection in each study hospital. The aim of this pilot period of fieldwork was to test and refine the proposed data collection approaches and tools. I also took this time to pilot and refine the methods of engagement with the hospital, the ward staff and the mothers as well as the participant selection procedures. This pilot phase of the fieldwork allowed me to explore and develop a strategy for engaging with mothers of sick babies and joining them on their journey through

care, from the time of admission through to the point of discharge. For some of the mothers, I was able to map out their journeys through their first post-discharge clinic review (usually conducted by the doctors managing the inpatient care) and the first few weeks of the baby's life at home.

As the layout of the NBU for each hospital was different, these initial weeks of fieldwork were important as it was during these weeks that I was able to map out and to identify: locations involving different intensities of care (e.g. acute room/compartments); how work stations were arranged; when mothers had access to these spaces and interacted with their babies; where different activities such as admission, discharge, feeding, washing, etc. took place. These initial observations also helped in identifying key times for focused observations; the best times and locations to talk to mothers that did not interfere with the medical or nursing process and that were most sensitive to the needs of the mothers; and potential locations for engaging mothers in subsequent data collection activities. Having done some preliminary observations and also found out from the mothers their thoughts on diary keeping, it was evident that diary-keeping was not feasible in the public hospital setting due to a number of reasons. First, mothers had no lockable lockers where they could securely store their personal diaries, secondly, it was not feasible for the mothers to keep audio diaries as the setting was very crowded, mothers shared beds and there was no private place within the NBU where they could audio record their diaries. Thirdly, mothers in the public hospital were heavily involved in looking after their babies, therefore asking them to spare time to keep diaries during the hospitalization of their baby was going to interfere with the caregiving process. Such ethical challenges of conducting qualitative research within hospital settings have also been observed in studies that involved interviewing of nurses, while nurses may be willing to take part in a qualitative interview, drawing them away from their shifts may compromise the quality of care in already understaffed wards (Jepkosgei et al., 2019). Finally, some of the mothers in the public hospital were illiterate, meaning they could not keep written diaries. As such, following discussions with my supervisors, we made the decision not to go ahead with the diary-keeping method.

The pilot fieldwork was particularly useful in terms of i) gaining familiarity with work routines and the personnel in busy sick newborn units; ii) informing strategies for ongoing data collection around specific patient/family journeys through care that did not interfere with care and that was sensitive to parents needs; iii) strengthening procedures for a continuous approach to information giving and consent; iv) supporting planning of additional specific discharge interviews v) finalising of the most suitable sampling strategy

and vi) allowing me to get familiar with the experiences of a neonatal unit as I am not clinically trained.

#### 4.5.2 Entry into the field and the fieldwork process

In each hospital, I started by obtaining approval to conduct the study at the facility from the hospital administration. Through the ward matron/nurse in-charge, I organised for sensitization meetings where I talked to the staff about my study. I also provided a copy of the study proposal and hospital approval letter to the nurse in charge, and this copy was kept in the nurse's station.

Following approval, I and TO spent 1-3 weeks of the preliminary phase of data collection in each NBU, familiarizing ourselves with the ward and its procedures through non-participant observations. The first 1-3 weeks involved hanging around the NBU from morning to evening. We moved across the different care spaces observing and interacting with the mothers. We had informal conversations with the mothers daily and observed the ward rounds, later each day after the morning ward rounds. We tried to spend time in all the care spaces. Using this approach meant that we met all the mothers on the ward from the initial admission days and walked with them throughout their journey in the newborn unit. There was no formal interviewing during these initial 1-3 weeks. We sat with the mothers most of the time. Spending a lot of time with them allowed my research assistant and I to explain to them what we were doing in the NBU and answered the questions that they might have had. This happened on one to one basis or at times in groups of twos or threes. My research assistant and I would each spend time in different rooms with the mothers, at times covering different shifts and days of the week.

I then began to conduct more focused observations in the acute room (described in detail in Chapter 5) building rapport with the mothers. Once I had created rapport with the mothers and the staff, I then identified mothers who met the inclusion criteria for further participation in the study, keeping daily contact with these mothers even as their babies moved to the stable baby's care spaces. As we kept in contact with them daily and observed the ward rounds, we were able to know when their babies were nearing discharge, at which point we asked them for an interview on the day of discharge. Those who consented were then interviewed on the day of discharge. This more focused and formal interviewing of the mothers in each hospital commenced after week 3 when we were certain that we had created rapport with all the staff working on the ward as well as with the mothers in the newborn

unit and I was confident that they were comfortable with our presence. At the point of discharge, we then consented and interviewed mothers. The entire *ethnographic data collection process* (figure 4.3) lasted for 10-14 weeks in each hospital. We conducted observations mainly during weekdays, covering morning and afternoon shifts. We also conducted observations of a few night and weekend day shifts. We then purposively selected a few women whom we visited in their homes for the narrative interviews.

#### 4.5.3 Recruitment of mothers

During the pilot fieldwork in each hospital, we had tested a strategy for the recruitment of mothers into the study. This involved identifying potential participants from among mothers whose babies were being cared for in the acute room/compartment but who were likely to be moved into a less intensive care environment within the following few days. While the babies were still in the acute room, we spent time building rapport with the mothers. Once their baby had been moved to the less intensive care environment, we approached individual mothers and asked if they would be prepared to be involved in further study procedures that involved participating in a discharge in-depth interview. We asked some of these mothers if they were also willing to participate in narrative interviews post-discharge (see figure 4.3).

#### 4.5.4 Forms of participation

There were three forms of participation in this study (see figure 1): i) Type 1 – the mothers who agreed to be observed; ii) Type 2 – the mother agreed to be observed and to participate in an audio-recorded discharge interview; iii) Type 3 – the mother agreed to be observed, to take part in a discharge interview and to be subsequently visited in her home where she was asked to tell the story of her experience in an audio-recorded interview. Data collection followed the same pattern of activities and we adopted a stepwise recruitment process. An outline of the process that was undertaken is provided in figure 4.2.

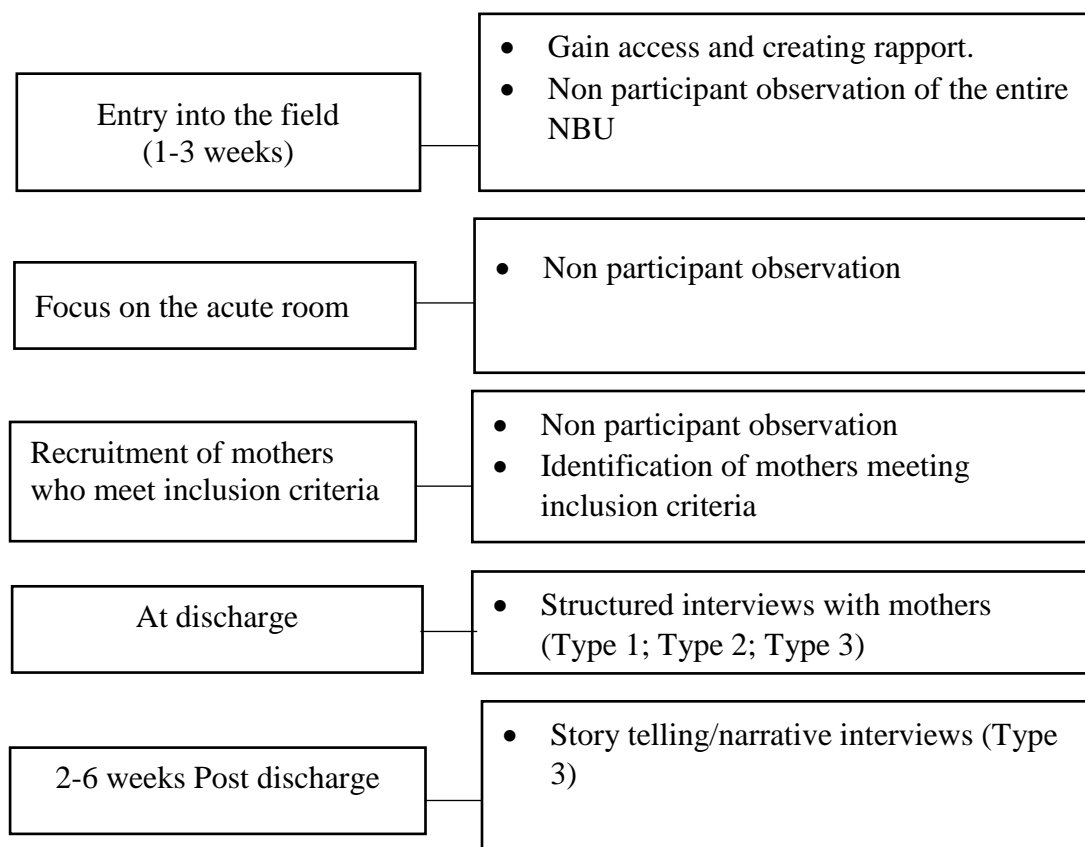


Figure 4. 2 Data collection procedure

#### 4.6 Data management and analysis

The data collected in this study was in the form of open text and audio files and included: field notes; audio recordings of the discharge interviews and narratives and the transcripts of discharge interviews and recordings of storytelling sessions. I used a grounded theory approach in the analysis of these data. This approach was advanced by Strauss and Corbin (1990, 1998). It starts with developing categories of information (open coding), followed by interconnecting the categories (axial coding) and finally building a story that connects the categories (selective coding), and ending with a discursive set of theoretical propositions (Strauss, 1990). Once I had collected the first set of data, that is, field notes and first few transcripts, I read the transcripts and the notes to familiarise myself with the data and started identifying the key issues and categorizing (labelling the data, coming up with the major codes)-open coding. In an ethnographic approach ‘writing is part of the analysis’ (Newnham, Pincombe, & McKellar, 2016). In naming the codes I combined ideas from the literature that I was interacting with as well as used the concepts and terms that the participants used in their interviews, in vivo coding to develop my coding framework (see annex F). As I continued to gather more data I carried on with doing constant comparison (Glaser, 1965).

Reading the new data set, applying the original codes and looking for new codes. Data analysis was a continuous iterative process, that also involved keeping memos of my ideas and thoughts about what I was seeing in the data and the codes. With more data, I reviewed the codes, identified new ones, renamed some and even started categorizing those which were related, axial coding. Once all the data were coded, I started looking for patterns, examining how the different categories were connected or linked to each other, iterative coding. I did this last step of coding visually, where I adopted a technique called the OSOP (One sheet of paper) (S. Ziebland & McPherson, 2006). I was able to come up with an OSOP that guided my thinking and writing up of the data, (see Annex G) for the OSOP I generated.

During fieldwork, my research assistant and I each kept field reports that captured descriptions of individuals, artefacts, events, practices, processes, interactions and our initial reactions and interpretations of the things we had observed (Creswell, 1998). My research assistant and I met weekly to reflect on the observations and our interpretations of the things observed. During the course of fieldwork, I also had regular meetings with my supervisors to discuss key emerging issues from our observations.

Formal interviews were audio-recorded and the recordings were then securely stored in a computer on password-protected files. The transcripts were then de-identified and the identification codes for the transcripts were kept in a separate secure location. All participants mentioned in the field notes were anonymized and any MS word file field notes were also securely stored in a password-protected file. After transcription and translation, the transcripts were imported into NVivo 10 for data management and analysis. Field notes (from observations and informal conversations) were also typed up and imported into NVivo 10. Internal validity of the study was ensured by audio-taping, verbatim transcription and checking at random for accuracy and completeness of interview transcripts. Data collected from all the sources were triangulated to ensure that different range of views and experiences were captured. In the analysis of these data, I applied a critical medical anthropology lens in the analysis of the data.

#### **4.7 Ethical considerations**

Ethical approval for this study was sought from KEMRI Scientific & Ethics Review Unit (SERU). I also obtained written informed consent from the mothers. They received information about the aims and process of the project and were informed of the possibility to discontinue participation at any time. Data gathered through interviews and/or observations were anonymized. Because the study involved a small number of participants,

particular attention was given to preserving anonymity. To protect the anonymity of the participants, each participant was assigned a unique Study Identification Number (SID). The nature of the ethnographic approach allows for information to be collected slowly over time through repeated conversations rather than in a single interview. This also provides opportunities for continuous information giving, clarification of information given and an ability to ensure participation is voluntary at multiple stages, ensuring participants can withdraw consent at any point if they wish. This immersive approach enabled us to provide ongoing explanations to all staff and mothers about the nature of the research, recognising that consent/assent in this form of research is a process of continuous information giving and permission seeking. Signed informed consent was obtained from the mothers who agreed to participate and the interviews were conducted in Kiswahili or English (depending on the mother's preference) and audio recording. During the home visits in order to compensate the mothers for their time, we gave them a small gift (a small pack of diapers).

Care was taken to ensure the confidentiality of all the information that was collected. All notes from non-participant observations were under lock or password. All audio files and data carriers were also locked in a safe cupboard.

#### **4.8 Reflexivity**

Just as the case is with other hospital-based ethnographies (Jepkosgei et al., 2019; Mulemi, 2008), I did experience a range of tensions and emotions in response to being in this emotionally charged environment. Both my research assistant and I struggled with coping with death and observing how mothers broke down after losing a child. This was something that the other qualitative researchers working on the larger HSD-N study also experienced. We were lucky enough to have the kind of support that was accorded to us. After raising these issues with our supervisors, we were taken through a series of communication and sessions on how to deal with emotionally challenging situations. The regular HSD-N qualitative researchers' reflexive meetings that we had as a group was also instrumental in helping us cope better, during these reflective meetings we would share the challenges and some of the ethical dilemmas that we encountered in the field.

During the initial week of fieldwork, I could clearly sense that some of the staff and the mothers were a bit conscious of our presence. During these initial days, we were outsiders. I observed moments of silence and short answers whenever we tried to engage with them. For the mothers, I did notice that whenever they were alone, they talked a lot amongst themselves, discussing their children and their lives at home. During our reflective meetings



with TO, we then decided that we would slowly by slowly try to be part of these mothers' groups. Continuously explaining to them what we were doing in the NBU, and them seeing us daily eventually broke the ice. Each day we would make an effort of greeting all of them, finding out how they were doing which they really appreciated. Some of them explicitly told us that for them it was nice to have someone whom they could talk to outside the NBU. We saw a change towards the end of the second week. The mothers eventually got used to having us around. There were days that I had meetings at the Office and TO would then go to the field by herself. I noticed that when I missed a day, whenever I went back some of the mothers would quickly point out that I wasn't there the previous day, and they would inquire about where I had been.

I was well aware during the design and at the beginning of this study that probably not being a mother myself could probably influence how I was viewed by the mothers. Although this did not affect the way the mothers interacted with me, during the recruitment of the research assistant, I made a pragmatic choice to select someone who herself was a mother. I observed that the mothers took solace in knowing that they were not alone. When they got used to us, they started to talk to us about their families, their struggles, turned to us whenever they had questions, they asked us things they could not ask the nurses (chapter 5). Those we visited at home for the narrative interviews really appreciated our visits. They would ask us about the other mothers whom they had left in the ward.

The main ethical dilemma that we faced in the conduct of this study was mothers turning to us with clinical questions and request for help with tasks, for example, some of the mothers would ask for explanations about what phototherapy was, why their babies were not allowed to feed, to help with the fixing of dislodged NG tubes. As we were not clinically trained, we took caution not to answer any medical question, we would politely refer them to a nurse for help or answers. Once I was asked by a medical officer intern who was fixing an IV line for help, a request I politely declined explaining to her that I was not skilled to help. Since my research assistant and I were employees of a medical research institute, from some of the staff we would receive a request from the nurses with help in securing jobs at KEMRI. These were some of the dilemmas that we faced in the field.

#### **4.9 Chapter summary**

In this chapter, I have discussed the conceptual framework that was informed by my literature review. In this study, I adopted a qualitative descriptive approach. In this chapter, I have also described my study design, data management processes, and analytical approach that I undertook. I applied an ethnographic approach to data collection, the data collection methods that I used were non-participant observations, in-depth interviews, and narratives. I used a grounded approach to analyse these data and a critical medical anthropology lens in the interpretation of the findings. I have concluded this chapter by reflecting on my positionality in the original research process. In the next chapters, I present the findings of this study.

## **5. RESULTS 1: THE CONTEXT OF NEWBORN CARE IN TWO NAIROBI HOSPITALS.**

### **5.1 Introduction**

In this first results chapter, I provide a picture of the environment that mothers of sick newborns find themselves in after their babies are admitted to hospital for inpatient care. I will describe the settings in which in-patient newborn care is provided in the two study hospitals; providing a picture of the structures, artefacts, and organisation of people within the spaces mothers inhabit while their babies are being cared for in these hospitals. For this chapter, I draw on data collected during the ethnographic fieldwork, which was conducted over 4 months in each of the newborn units. I provide a reflection on the contexts I observed.

The chapter is divided into five sections:

- Section 5.2 provides an overview of the general characteristics of each of the two hospitals, their locations and mothers and patients they care for.
- Section 5.3 contains a description of the internal structure, artefacts, physical and social environment of the NBUs.
- Section 5.4 describes the organisation of care, as well as the costs of care for each study hospital.
- Section 5.5 contains a description of the trajectories of care, staffing ratios, and organization of the shifts in the newborn units of each hospital.
- Section 5.6 discusses the findings, focusing on the implications of the observed differences in the socio-economic context on the structures and the artifacts and the people and their practices of care.

### **5.2. General characteristics & structure of the two hospitals**

The two study hospitals are located in Nairobi City County and are both easily accessible by road. For the purposes of this thesis, the two hospitals are referred to as Kijani and Tausi (figures 5.1 and 5.2).

Kijani is a public hospital, located on the edge of Kibera, the largest slum in Nairobi. Tausi is a faith-based hospital located in an upmarket area. Both facilities are within 10 kms from the city centre and roughly about 8kms from Kenya's largest referral hospital, Kenyatta National Hospital (KNH). KNH serves as the most common point of referral for babies

requiring more specialised care for both study hospitals. Babies requiring certain laboratory tests as well as specialised imaging services that were not available in Kijani hospital would also be referred to KNH. Tausi hospital on the other hand had the capacity to carry out these tests and imaging services. A general description of the two hospitals is provided below.

### 5.2.1 Kijani hospital

Kijani was built in the 1950s to offer health care services, mainly for infectious diseases requiring isolation such as tuberculosis, measles, meningitis, and leprosy. It is a 200-bed capacity busy public hospital, offering low-cost care for outpatient and inpatient services. Services available include surgical, maternal newborn and child health (MNCH), laboratory and radiology. At this facility, MNCH services have been offered free of charge since 2013, in line with the national government directive to abolish user fees for under-fives in all public facilities (Health, 2015; Tama et al., 2017). The hospital's departments are spread out across various buildings within the hospital grounds. The newborn unit was housed on the first floor of a newly built maternal and newborn unit, a two-storey building that became operational in 2014. On the ground floor of this building was the maternity ward (figure 5.3).

The hospital cares for high numbers of women seeking maternity services and babies needing NBU care. Its location next to the largest informal settlement in Nairobi makes it accessible in terms of distance for the poor vulnerable population living in this settlement as well as families of low socioeconomic status. Most of Kijani hospital's patients are from Kibera, the largest slum in Nairobi where the majority of residents live below the poverty line- earning less than a dollar per day. Unemployment rates for people living in this area are generally high. The main source of income for people living here is the informal sector employment; the majority are small scale traders selling things at the roadside or are engaged in daily labour such as working in building construction sites and the women offer cleaning services in the neighbouring middle and upper-class neighbourhoods.

### 5.2.2 Tausi hospital

Established in the 1970s, Tausi is a mission hospital that offers both inpatient and outpatient services (figure 5.2). As a church-run hospital, the facility aims to offer these services at a subsidized price compared to other existing private hospitals in Nairobi. However, the cost of care is relatively higher in Tausi in comparison to Kijani. This hospital is housed within a seven-storied building and has a bed capacity of 157. The specialised newborn unit and maternity ward are alongside each other on the sixth floor. The ground floor of the building

houses the X-ray and imaging services. On the first floor, there is the reception, a canteen, outpatient and emergency sections. Floors two to seven house various other departments and wards. Tausi hospital serves a mainly middle-income population in Nairobi County with patients drawn from across the city. Data from the Nairobi newborn study (Murphy et al., 2016; G. A. V. Murphy et al., 2018) (Murphy et al., 2016; Murphy, Gathara, Mwachiro, Abuya, & Aluvaala, 2018) show that women seeking maternity services in this facility come from widespread middle-income<sup>2</sup> localities around Nairobi. Compared to Kijani, the hospital receives fewer numbers of women seeking maternity services and babies needing NBU services, a factor that could mainly be attributed cost, see section 5.4. Unlike in Kijani, MNCH services in Tausi are offered at a cost.

The public hospital Kijani had a high number of babies. The admissions for critical and the stable babies on the NBU were evenly split between the critical babies and the stable babies' wards. This was not the case with the faith-based hospital. It had a much lower admission level, but there were more babies in the general ward (care space where stable babies were admitted into) compared to the numbers on the critical wards (care spaces where very premature and very sick babies were admitted into). The range of reasons for admission across the two hospitals was prematurity, jaundice, congenital malformations, and infections. Only Kijani hospital also housed some abandoned babies<sup>3</sup>. The most common cause for admission for Kijani was prematurity and jaundice while in Tausi a number of babies were admitted for infections and jaundice.

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<sup>2</sup> As defined by the Kenya National Bureau of Statistics, the middle income comprises of anyone spending between USD 233 and USD 1970 per month.

<sup>3</sup> In public hospitals, abandoned babies are those that are born in hospital and their mothers abscond leaving them behind in hospital. These babies though not sick, are cared for in the NBU till transfer to a children's home is facilitated through the hospital's social services department.

### 5.2.3 Available artefacts and equipment

Present on the NBU ward of both study hospitals were essential and specialised equipment.

Table 5. 1 Availability of equipment in Kijani and Tausi

	<b>Kijani</b>	<b>Tausi</b>
Oxygen equipment	✓	✓
Phototherapy equipment	✓*	✓
Blood pressure machine	✓	✓
Cots	✓*	✓
Incubators	✓*	✓
Radiant warmers	✓	✓
Sink with soap and running water	✓**	✓
KMC rooms with beds	✓	
Medical digital weighing scale	✓	✓

\*Shared >1 baby in the same cot/incubator

\*\*Irregular supply

## 5.3 Internal structure: Environment, spaces, and artefacts in the newborn units

### 5.3.1 Kijani hospital

In Kijani hospital the maternity unit and post-natal wards are housed on the ground floor of the purposively built block with the neonatal unit on the first floor (Figure 5.3). From the main entrance to the building there are three ways to get to the newborn unit: (i) via a ramp next to the centrally placed security desk on the ground floor (ii) through a flight of stairs by the entrance to the delivery wards; and (iii) up a flight of stairs next to the entrance to the post-natal ward. Visitors and staff working in the NBU mainly used the second route while the mothers with babies in the NBU generally used the third route to access their babies in the NBU from the postnatal ward where they slept. These mothers would walk up the stairs to the first floor and across the corridor that leads to the entrance of the NBU, on the right of the building (Figure 5.3).

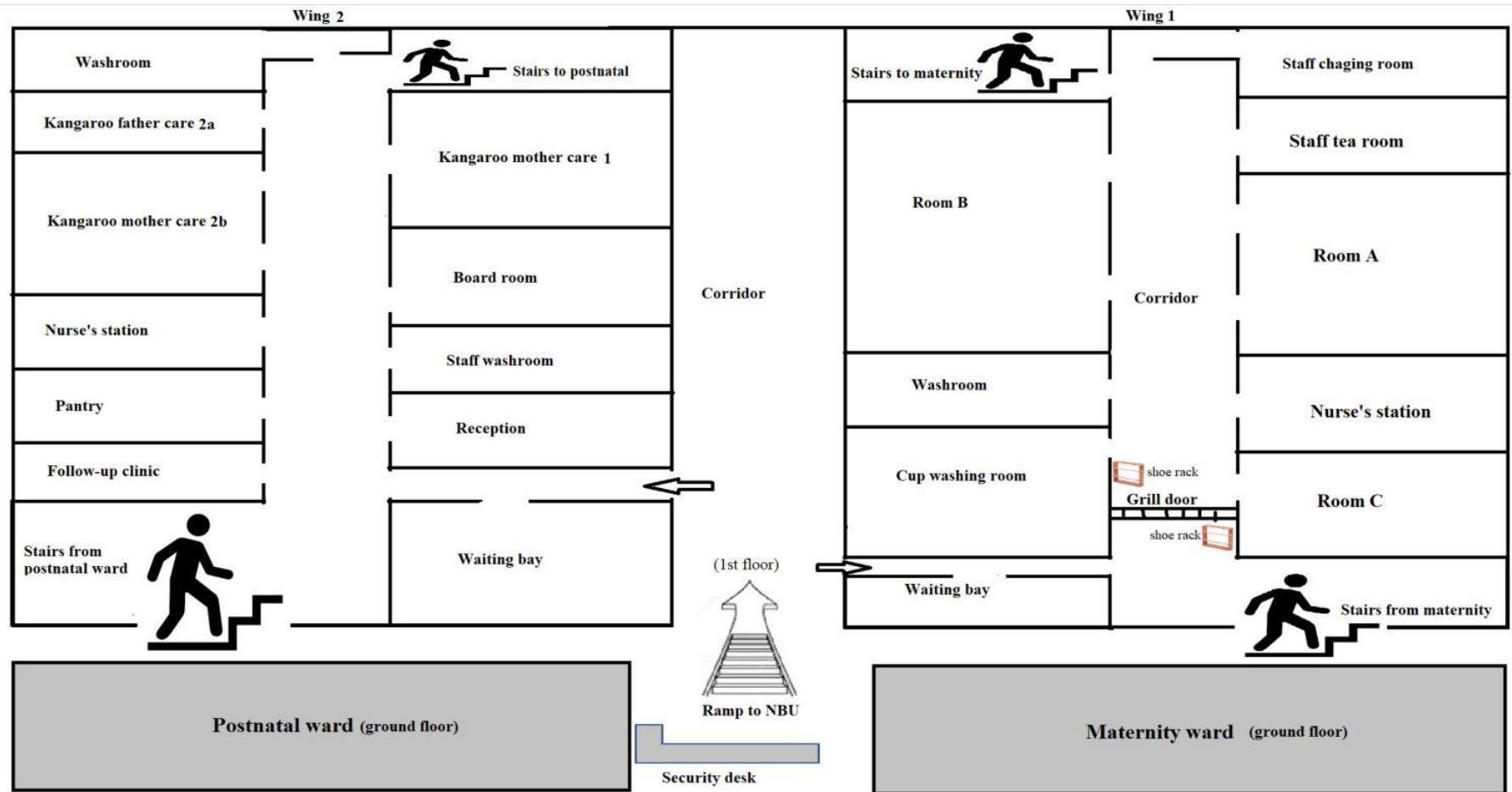


Figure 5. 1 Layout of Kijani

### **Outside the NBU.**

Throughout the data collection period, there was always a beehive of activity outside the maternity and NBU building and in the waiting area on the ground floor. Gathered outside or at times sitting on discoloured wooden benches in the inside waiting area by the entrance, were relatives of the mothers in labour. There was another waiting area on the first floor outside the NBU where relatives to the women whose babies were admitted to the NBU would sit during visiting hours. The relatives would be engaging in conversations in low tones as they patiently waited to see their relatives.

Every mother whose baby was admitted as an in-patient in Kijani was expected to remain in hospital until their baby was discharged. The sleeping area for mothers with babies admitted to the NBU was located on the ground floor in the postnatal ward (Figure 5.3). Due to the high numbers of mothers delivering in this hospital, beds were often insufficient. Finding a space to sleep was on a first-come-first-served basis. At times when the post-natal ward was full to capacity, mothers would spend the entire night in the NBU next to their baby's incubator or cot either sitting on the plastic chairs or sleeping on the wooden benches or sleeping on the floor. Observations carried out at night revealed that the mothers would just spread *lesos* (colourful cotton printed rectangular cloth) on the floor and catch a few hours of sleep while those who dozed off on the chairs just covered themselves with *lesos*.

Although sleeping arrangements were minimal, during their time in the hospital the mothers were provided with three meals a day at no cost. Meals for mothers with babies in the NBU were served in the postnatal ward. Breakfast (served at around 6 am) was a cup of porridge, followed by lunch at 1:00 pm and then supper at around 6:00 pm. Hot water for beverages was also provided once a day in the morning mainly for those in the kangaroo mother care (KMC) room. KMC is the practice of providing continuous skin-to-skin contact between mother and baby. They were provided with a tin of drinking chocolate and sugar. Each mother in the KMC had their own utensils.

### **Getting to the NBU**

Going through the stairs by the maternity, using the pathway used by visitors and staff, I would daily come across women in labour pacing up and down the corridors of the maternity ward and by the waiting area, while some sat writhing in pain on the floor or on the stairs leading up to the NBU. There were frequently screams from the women in labour or the delivery room on the ground floor. Additionally, a strikingly unpleasant odour filled the air,



a combination of blood from the maternity ward, damp mops used in cleaning the floors as well as body odour in the crowded ground floor. However, while during the first phase of data collection the smell was occasionally overpowering, going back to the facility in phase 2, I noticed that the floor was very clean and that it smelled differently; the air was fresh and at times filled with the smell of detergent. At this time, just at the beginning of phase 2, there were volunteer nursing/clinical students from a local private university who were doing community service at the facility and they helped to thoroughly clean the NBU. These community service students came in only on weekdays and each morning, they religiously scrubbed the floors and washed the walls. After their departure, a newly employed cleaner started working on the NBU and slowly over time things went back to the way they were in phase 1.

In phase 1 of data collection in Kijani, before the start of the nurses' strike (see chapter 3), despite the hive of activity, there was a sense of order in the NBU made visible by the commitment of the nurses to the restriction of the flow and number of visitors in and out of the NBU. Additionally, during phase 1 of data collection, there was also a very strict security guard stationed by the entrance to the maternity and NBU building. This security guard would keenly keep watch and control visitors entering the maternity and NBU wards outside the visiting hours. I recall that on my first day of data collection, she stopped me and asked where I was headed to, "*you must register*" she told me. It was only when an NBU nurse who happened to be passing by found me standing by the security desk and stopped and informed the security guard that I would be a regular visitor to the NBU that I was allowed to enter. From then on, my entry to the ward was easy. Only fathers were allowed to enter the NBU during the visiting hours. During phase 2 of data collection in Kijani (after the nurses' strike) (see chapter 3), there was a change of the personnel, a newly employed security guard had reported and there was a rotation in the nursing staff that saw four nurses transferred to other wards and replaced with new ones. The new personnel were not as strict as the previous ones and laxity in control of visitors crept in. It was now common to find relatives flocking into the NBU at visiting hours and at times outside the visiting hours.

### **Entry to the NBU – crocks and bare feet**

The entrance to the newborn unit on the first floor was guarded by an iron grill door. In phase one of data collection, this grill door was always closed, however in phase two of data collection, the grill door was most of the time left ajar or wide open. Boldly printed in black on a white piece of paper that was stuck up on the wall before and past the grill door was a notice that read "NOTICE NO VISITORS BEYOND THIS POINT" (figure 5.4). On many

occasions during phase 2 of data collection, I saw these notices being ignored. All visitors to the ward, including the mothers, were required to remove their shoes before they entered the ward through the iron grill door. There were two shoe racks by the entrance, one just outside the grill door for use by the mothers and relatives and a second one located in the corridor past the grill door, for use by the nursing and clinical staff (figure 5.4). It was during my orientation into the NBU by the nurse in charge in phase 1 of data collection, that I became aware of the separation of the shoe racks. I had removed my shoes and left them outside, but she quickly told me to place my shoes inside on the second shoe rack. I later asked one of the nurses the reason why the mothers had their shoe rack outside, *“you might not find your shoes if you place them out there, some of these mothers steal, they may walk away with your shoes”*, she explained. Her views together with the separate shoe rack to me were the first indicator of the staff attitudes towards these mothers. To a number of the staff, these mothers could not be trusted, were of a lower class and maintaining a level of hierarchical distance from the mothers was paramount.

There was a bit more order in the hospital staff’s shoe rack than in the rack used by mothers and visitors. After removing their shoes, most of the hospital staff would place them on the shoe rack but some would keep their shoes under a table in the nurses’ station. Crocks, which the staff wore while in the NBU, were either placed on the staff shoe rack or at times left lying on the floor by the shoe rack. These crocks were shared amongst the staff. I noted there were a few members of staff who had their own crocks and would store them in a box in the nurses’ station or in the nurses changing room at the end of their shift. By contrast, there was no order in the mothers’ shoe rack and no crocks or other forms of footwear were provided. In the second phase of data collection, the mothers’ and visitors’ shoe rack was moved away from the grill door and placed right next to the staircase. Scattered in a mess on the floor next to the mothers’ shoe rack and later in the second phase outside by the grill door away from their shoe rack were dusty pairs of sandals and shoes belonging to the mothers and their relatives. Once they removed their shoes/slippers, the mothers walked barefoot into the NBU. Some of the mothers, however, would walk barefoot all the way from the postnatal ward on the ground floor. Dependent on the mother’s strength it could take anything between 5-10 minutes to walk from the postnatal ward to the NBU. For those who had delivered through caesarean, this journey took even longer. Mothers often complained about the need for frequent walking up and down the stairs to and from the postnatal ward where they slept to the NBU.



Figure 5. 2 Entrance to Kijani NBU

### *Inside the NBU – spaces and artefacts*

The NBU was very bright and hot. In the mornings, the smell of the cleaning detergent used in mopping the floor was potent. The floor was mopped once a day except on the occasions when the water tanks on the roof above the main corridor overflowed. When this happened, the entire NBU flooded, and the cleaner would mop the floor again. In phase two of data collection, the overflowing tanks had been repaired.

The NBU ward has eight rooms arranged along a corridor with three rooms on the left-hand side, four rooms on the right, and one room at the end (figure 5.3). Once through the NBU's grill door, the first room on the right-hand side of the corridor is room C. This is the smallest of all the care rooms and is allocated to all sick neonates referred to the unit from other facilities or readmitted after discharge. This room had 2 incubators, cots, and two phototherapy machines. Whenever there were many admissions, each cot and incubator in this room was shared by two babies. Unlike the other care spaces in the NBU, the entrance to this room had a blue wooden door that remained shut at all times. As described by the clinical and nurse interns who were rotating in the NBU during phase one of data collection "*it is the stuffiest room*" in the unit, and most of the interns disliked working in room C. At any given time, there would be between 6 to 10 newborns in room C with their mothers continuously by their side caring for them. They sat on chairs next to their baby. Its location, just before the nurses' station, meant relatives could occasionally sneak in to visit the mother and baby. Access for relatives to the other care spaces was much more regulated and restricted in phase one of data collection, probably because the nurses had a lot more help from the nursing students who were on rotation to help with the nursing tasks. In phase two, however, things changed, without the presence of nursing students, the nurses rarely paid

attention to check on who was entering the NBU. There was also a change in the personnel (nurses and security guard). Visitors would bring cooked food from home for the mother.

Opposite room C is a wash-up room where mothers clean the utensils/equipment they use for feeding and washing their babies. Nasogastric (NG) tube feeding in this hospital was undertaken by the mothers (see chapter 6 section 6.3) and each mother was equipped with an ordinary cup (provided by themselves) and syringes for feeding (provided by the hospital). There was no provision for storage of expressed milk in this facility. The room contains a sink with a tap with cold running water; this was the only tap that always had water in the NBU. Next to the sink on the working surface, there were three pink buckets labelled, 'clean water', 'soapy water' and 'jik/bleach water'. These buckets were meant for cleaning the feeding syringes and cups. Mothers identified their cups by the colours, and some had inscribed their names on the cups. Very rarely would a mother take a cup that didn't belong to her. They would store their feeding cups and syringes in the drawers by their babies' incubators or next to their cots. Also kept in this wash-up room were small green basins that were provided for the mothers and which they used for top tailing (washing) their babies. The basins were neatly stacked and kept next to the pink buckets. There was also a cabinet and some shelves in this room where supplies such as saline for IV and cleaning detergent were stored.

### **Nurses' office**

The second room on the right-hand side of the corridor is the nurses' office. There was a cabinet where files were stored and a refrigerator where only drugs were stored. In between the cabinet and the fridge was a red treatment tray. Next to the fridge, there was a table where treatment files for babies currently in-patients in the unit were placed in stacks, separated according to the room where the baby was. At the end of the ward round, all the files would be put back on this table. There was a table and chairs in this office for the nursing and clinical staff. Hung up on the wall in the office was a calendar as well as handwritten guidelines and phone contacts of NBU staff and other hospital departments. Daily, after the ward rounds and at times during handover sessions, nurses and clinicians used this space to complete their manual paperwork. There were no computers or desk phones in this NBU. The staff would use their own personal mobile phones for communication. The nurses' office was also the first point of call for visitors to the NBU. Whenever a baby died, the parents and other relatives would briefly meet with the staff in this room.

## **Acute room**

The third room on the right-hand side of the corridor (Room A) was separated from the nurses' office by a half glass wall - the lower part was concrete. This room was where babies when first admitted from maternity and very sick babies requiring constant monitoring, as well as those requiring incubator care and phototherapy care were placed. Through the glass from the nurses' office, the nurses could clearly see inside room A. In a corner of room A, by a window and adjacent to the glass partition, there was a radiant warmer where very sick babies were placed. There was a second radiant warmer on the opposite end of room A. Unlike the incubators, these two spaces were never shared. Over the time of my fieldwork, both radiant warmers were in use almost daily; babies placed in the radiant warmer could stay in for 1-2 days before being transferred to incubators. However, very critical babies would be transferred to the national referral hospital for specialised care. It was also common for very critical babies from room C to be moved to these radiant warmers and at times babies from outside the NBU would be rushed directly into these resuscitators. Consequently, due to the limited resources, the isolation policies, present on paper, were not adhered to.

In addition to the two radiant warmers, room A contained twelve incubators which were mostly shared by two babies at a time. It was usually the nurses who decided which incubators a baby would be placed in. Three of these incubators had phototherapy machines where babies with jaundice were placed. Only the two incubators located right next to the radiant warmer were connected to oxygen outlets on the wall. Babies in the other 10 incubators requiring oxygen therapy would be connected via portable oxygen cylinders. It was also very common for babies to be shifted from one incubator to another depending on need. When there were no portable cylinders and where there was a baby not requiring oxygen in the ones connected to the piped oxygen from outlet on the wall, babies would be moved. A baby requiring phototherapy but who might have been initially placed in an incubator without the phototherapy machine would also be moved to an incubator with the machine. The clinicians would occasionally move the babies but then inform the nurses about the change.

Alongside each incubator, plastic chairs were provided for use by the mothers during feeding. Each morning during the ward rounds, mothers would sit on the plastic chairs by their baby's incubator. Chairs were separated like shoes. Just as there is a separate shoe rack for mothers and nurses, the nurses rarely used the plastic chairs even if they were available. Instead, they sat on the wooden bench or stools. I later came to learn during a conversation

with an intern that the staff avoided the plastic chairs because some of the mothers lacked sanitary towels and would walk around in stained gowns.

*“At the end of the ward round, I sat on one of the plastic chairs that was close to the nurses’ station in room A. Julia one of the interns turns to me and says “aren’t you scared of sitting on those chairs?”, perplexed I responded telling her I wasn’t and asked her why. She told me “we don’t like sitting on them because some of these mothers’ wear blood-stained gowns” (Field notes\_Kijani hospital)*

In the middle of the room was a table with wooden benches and stools at either end which functioned as the nursing station. The staff used this as a space for completing their paperwork during the ward rounds and at times to rest. During ward rounds this station would be covered with the documents used to record the treatment plans and notes about the babies; files, nurse’s kardex and papers lying in a mess. At the end of the ward rounds, the table would be arranged and cleared by the clinical officer interns who would move the files to the nurses’ office.

Room A also contained a sink that at times had running cold water and soap provided for use by the staff to wash hands in between procedures. Next to the sink was a table that was mainly designated for storage of unused syringes, gloves, weighing machine and iv fluids. The atmosphere in room A was often tense and sad. There were continuous loud beeping noises and alarms from the incubators. Alarms were frequently silenced, by nurses, and by mothers following their example. Which button to press when the alarm went off was one of the things mothers showed each other. They would rarely call for help from the nurses when the alarm sounded or asked why the alarms sounded.

No more than two to three days would ever go by without a baby dying in room A. These were the saddest days. The mother whose baby had died or whose baby was deteriorating would often panic and wail bringing everything to a near standstill. When a mother was in that state all the other mothers sat in groups, sadly watching and talking about this in low tones among themselves. They feared about their babies dying too. The mothers of babies who were deteriorating or had suffered a traumatic event were concerned about leaving their babies. They would sometimes doze off on the plastic chairs, and even when encouraged to go rest in the postnatal ward by a nurse or other mothers they declined, choosing to sit right next to their sick baby.

Room A was a very emotionally charged and challenging setting not just for the mothers but

also for me as the researcher. I really empathised with the mothers when this happened, being in this emotionally charged environment and observing the things that this vulnerable group went through was very challenging. There was often lack of consumables, the NBU nurses were overstretched but still tried their best to care for the sick babies.

### **The nurses' tea room**

The final room on the right-hand side of the corridor is the staff tea room. Every day, at around mid-morning, the hospital provided plain tea and hot water for the staff working in the unit. There was a cold water sink by the only window in the room which most of the time had running water. There were a few chairs, two tables as well as two storage cabinets. This space was where the nurses had their tea, rested and had a few minutes to catch up and tell stories. The staff often closed the door on the rest of the unit whenever they were having tea or resting in this room. This was clearly a nurses-only space where mothers were not allowed to enter. One day a young mother whose baby had been admitted after the ward round wanted to clean her baby. However, as hot water for top tailing was only provided very early in the morning she was stranded. The other mothers who had been in the unit longer tried to help by advising her to look for the cleaner to get her hot water.

The cleaner was not in the NBU, and one of the mothers called me and said: *“are you allowed in this room?”- pointing to the tea room- “us we are not allowed in here, could you get her hot water so that she can clean her baby?”* This was one of the many times when mothers would turn to me for help; in this instance to help access a space that was clearly viewed as outside the reach of the mothers. At the end of the corridor, directly facing the entrance was the staff changing room. In this room are toilets, showers, a cabinet and hooks for hanging coats used by the staff.

### **When the baby gets better.**

Past the staff changing room and walking back down on the opposite side of the corridor, room B is opposite room A (figure 5.3) and had two exits, one closer to the tea room and the other towards the exit to the NBUs. Once stable, babies were transferred from room A to room B. The layout of the rooms was similar except that there were only one incubator and eleven cots, most of which were shared by babies. As in room A, there was a centrally placed table with wooden benches. The table and benches were used by the staff primarily when they were completing documentation during the ward rounds. There were also plastic chairs for the mothers. Room B was generally not as crowded as room A since there was less

equipment and it was usually only occupied by the mothers in the morning during top tailing and at the stipulated feeding times. As the babies in here were stable, mothers in room B were not as worried and tense as those in room A. Mothers tended not to spend as much time in here as they did when their baby was in room A. In addition to the three hourly feeding and morning bathing times (described in greater detail in chapter 6), the presence of mothers was required in this room during ward rounds, when they sat on the plastic chairs next to their baby's cot/incubator.

Nurses were rarely present in room B, apart from during the ward rounds and medication routines. They concentrated more on room A where critical babies were. As in the other rooms in the NBU, mothers talked to each other, but they talked more often and more freely when they were on their own than when the nurses were present. In all the NBU spaces, mothers would generally interact with the nurses and clinicians when they needed practical assistance with equipment and procedures such as when they needed to remind the nurse or clinician to fix IV fluids and NG tubes. During the ward rounds, the mothers would be asked questions by the doctor and medical officer or clinical officer interns. Questions asked included whether the baby was feeding well and if they had noted any problems. It is also during the ward rounds that mothers were informed by the doctor about the required laboratory investigations and x-rays especially if these were to be done outside the hospital and had financial implications for the mother. For the blood tests to be done at KNH, the mother was often asked if and when the husband or any relative would be visiting since it was for them to take the blood for testing at the national referral hospital. The drawn blood was put in a vacutainer tube and then placed in a latex glove and handed over to the mother with a laboratory request form and instructed to hand it over to the husband or a relative. The mothers would often ask about the progress of their baby and about how much milk to give the baby. The staff attending to the baby would respond to these questions informing the mothers of the baby's progress and instructed the mothers on the quantity of the prescribed milk.

### **Linen and clothing**

Clean and dirty linen for babies from rooms A, B and C were placed in two cots in this room, one cot for clean and the other for dirty linen (figure 5.5). The linen for the cots as well as gowns for the mothers was provided by the hospital. All mothers with babies in the NBU were required to wear a blue gown. Some of the mothers wore the gown on top of their own clothes, others often wrapped *lesos* -cotton cloth wrap- on top of the gowns. The babies in this hospital did not wear gowns as these were not provided, only the mothers had gowns.



Babies in room A, C and KMC only had diapers on, those in room B would be dressed by their mothers in their own baby clothes. It was the role of the cleaner to take dirty linen to the laundry and bring in fresh linen and gowns from the laundry. She would take them after she finished cleaning the floors. At times she would return empty-handed reporting that there was no clean linen in the laundry.

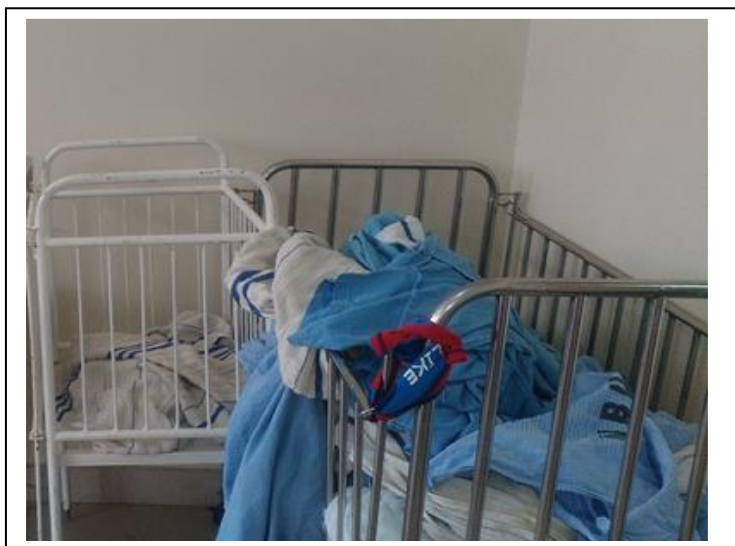


Figure 5. 3 Clean and dirty linen cots

At times there would be a shortage of linen and gowns. This was because some of the mothers would hoard extra gowns and linen. They stored extra linen in the drawers of the incubators where their babies were and took extra gowns back with them to the postnatal ward. However, there was a communal sense in that if there was a mother who had no linen for her baby's incubator, other mothers would donate one from their "hidden stock".

Next to the dirty linen cot, there was a cot where corpses of babies that had passed away in the NBU were placed. This was visible to the mothers. Whenever a newborn died in the NBU, their bodies were wrapped and placed here on this on this cot in room B. At times the whole cot would be covered using a larger sheet. The bodies remained in this cot for hours at a time, even days, pending clearance and transfer to the morgue or release to the family for burial.

### **Kangaroo mother care (KMC)**

In addition to the rooms in the main NBU, the unit also had a KMC section located on the same floor but in the opposite wing (figure 5.3). Earlier during phase 1 of data collection,

KMC was done in these two rooms; KMC room 1 and in a smaller room (KCM 2a). There was a reorganization of the KMC section in phase two of data collection. In March 2018, the room that had previously been KMC 2a became a KFC room (Kangaroo Father Care room). A larger new KMC room that was labelled KMC2b was created right adjacent to the KFC room. KMC1 housed six beds, a radiant warmer that was transferred to the new KMC 2b, one room heater and a poster of a guide to KMC on the wall. In the new KMC2b, there were 11 beds, a sink which had cold running water and soap at all times, a table where flasks of hot water were placed, cocoa, and some sugar in a tin that was provided for the mothers. There were several heaters distributed around the KMC rooms and mothers improvised a way of heating water, they would place water in plastic bottles next to the heaters. They used this hot water for bathing themselves and at times top tailing. The KFC room had two beds. KFC was introduced by the nurse in charge in phase 2. Fathers were encouraged by the nurse in charge to assist the mother with kangaroo care though the uptake was very low, during the period of my fieldwork this room was never used. The doors to all the KMC rooms remained shut at all times to prevent draughts. A mothers' washroom was located at the end of the corridor outside the KMC rooms. During phase 1, one of the rooms on the KMC wing was assigned as a store for the mothers and was used by them to store their bags. This store was later turned into the review clinic room and mothers kept their bags inside the KMC room by or on their beds. Along the dimly lit corridor of the KMC wing, there were benches where mothers who had brought their babies back for weekly review post-discharge, sat as they waited for their turn in the clinic.

The KMC room was cleaned once a day in the morning and neither mothers nor visitors removed their shoes to enter this room. The atmosphere in the KMC room was often jovial unlike in the main NBU. On each bed a mother lay with her baby; there was no bed-sharing. Often mothers would sit on their beds telling stories and laughing with their baby lying next to them. After bathing the babies, they would dress the babies in clothes they had brought with them to the hospital. This defeated the purpose of KMC as with KMC mothers, in essence, mothers are supposed to practice continuous skin-to-skin with their premature babies. Nurses would often complain and repeatedly urge the mothers to practice KMC whenever they walked in and found this happening. The nurse in charge would ask, "*mothers, why aren't you doing kangaroo?*" and the mothers would respond by telling her that they were just taking a break. She would go on to talk to them about the benefit of KMC. Mothers used their *lesos* to strap their babies in kangaroo position.

I remember running into one of the champion mothers/peer support mother<sup>4</sup> whom I had met in the early days of fieldwork. She was outside the KMC room and she was also concerned that the mothers had dressed their babies and were not practising kangaroo. *“These mothers are not serious, us (referring to her cohort of KMC mothers) we would never cloth our babies and our babies were always on kangaroo”*. Mothers in KMC would enjoy their meals in the KMC rooms. For breakfast, porridge in a flask was brought to them. For lunch and supper, they had to walk downstairs to the postnatal ward when meals were being served, after which they would walk back up to the KMC room with their food. The KMC project was supported by Save the Children who donated the beds, trained the nurse in charge and provided money for transport that supported home follow up visits and a token for the two champion mothers. The champion mothers’ role was to help with the follow up of mothers who had given birth to premature babies and give health talks.

### **5.3.2 Tausi hospital**

The architecture of this mission hospital was very different from that of Kijani hospital. Unlike in Kijani hospital where all the departments and wards are physically separated over different blocks, this mission hospital had its departments located within one eight-story building. This building was relatively new, having started operation three years ago in 2015. The maternity ward, newborn unit, and the postnatal wards are all located on the expansive sixth floor accessible via lifts from the ground floor. The entrance to the NBU is through a wooden brown door that remained shut most of the time. This door was clearly marked NBU and a notice printed on white paper stated: “no visitors allowed”. Apart from the security check on the ground floor, there wasn’t a security guard permanently stationed on the sixth floor outside the maternity and NBU to monitor the flow of visitors as the case was in Kijani. Entry of visitors into the Tausi NBU was closely monitored by the nurses on duty. There was only one entrance to the NBU which was used by all.

In contrast to the atmosphere in Kijani hospital, the environment in this facility was quieter and very serene. The NBU is adjacent to the maternity ward, with the postnatal wards on the opposite side of the floor (fig 5.6). Some of the mothers who had been discharged from maternity but still had babies in the NBU opted for their voluntary discharge in order to

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<sup>4</sup> Champion mothers were mothers whom themselves had delivered premature babies in Kijani hospital. Having stayed in the hospital for several weeks, they had been selected as part of an ongoing project as volunteers. This project was supported by the Save the Children and these champion mothers offered peer education to mothers whose babies were hospitalised. They focussed on talking and teaching the mothers about KMC and also assisted with the home follow up for mothers who had defaulted from their return follow up appointments post discharge.

reduce the costs (see section 5.4). Other mothers who had been discharged from the maternity ward, chose not to go home, remaining in the hospital throughout their baby's admission, paying for accommodation in the postnatal ward. There were two postnatal ward options available, depending on how much money the mother had: i) executive - a private single-occupancy room; and ii) shared room - two beds separated by a curtain. Both types of rooms had television sets and two chairs for visitors. The design of the rooms allowed mothers to have some private time with their visitors as the beds were not shared. Meals were provided at a cost for the mothers (morning tea, ten o'clock tea, lunch, 4:00 pm tea and dinner). Similar to Kijani hospital, visitors also brought food from home during visiting hours. Tausi hospital was much cleaner, smelt fresher, was less crowded and more structurally organized than Kijani, and the newborn unit was more serene.

There was a waiting area right outside the NBU in Tausi where visiting relatives would sit, often those who had accompanied mothers to the maternity. This waiting area exhibited way less activity compared to the situation in Kijani, this could be because visitors were able to visit the mothers in their rooms and also because Tausi hospital recorded far less admissions to the maternity compared to Kijani. Behind this waiting area, there was a lobby also on the 6<sup>th</sup> floor that had black leather sofa seats where the mothers who had been discharged from the hospital but still had their babies as inpatients in the NBU would spend most of their time during the day. Observations, as well as informal conversations with the mothers and nurses, revealed that some of those mothers who had been discharged would come in daily spending the whole day in the hospital, while a few would be present only for a few hours.



Figure 5. 4 NBU layout Tausi hospital

### Inside the NBU

The NBU in Tausi is accessed through a changing area (room 1). Both the mothers and staff used the same access to the NBU. In this changing area was a shoe rack used by both staff and parents, with neatly arranged shoes and red and blue slippers. Next to the shoe rack, there was a small wooden cabinet where blue shoe covers were kept. The slippers and shoe covers were available for use by both the mothers and staff, mothers in Tausi were not expected to walk barefoot inside the NBU as the case was in Kijani. There was also a metal cabinet with lockable shelves where staff kept their personal items. Behind the wooden entrance door were hooks for hanging coats and sweaters. Hanging on hooks on the wall were blue gowns for parents to wear over their own clothes while visiting their hospitalised babies. White tiles covered the floor surface of the entire unit. A distinct red line on the floor in room 1 clearly marked the point beyond which shoes were not allowed. This NBU had a

fresh smell, often that of the detergents and antiseptic used in cleaning the floor, windows, and surfaces.

The first room to the left inside the NBU, room 3, was the nurses' washroom which also doubles up as the nurses' changing room. Next to the nurses' washroom was a handwashing area, room 16, where mothers and fathers washed their hands. Liquid soap and paper towels were provided in this wash area. Placed on the wall right above the tap was a poster on proper handwashing technique. Unlike in Kijani hospital, Tausi always had running water in the taps, liquid soap and paper towels available and hand sanitiser dispensers distributed in the NBU. Adjacent to the parents' hand wash area, which was only available in Tausi, was the breastfeeding room (room 15). The glass partitioning separating the different care spaces and rooms 6-15 added to the brightness of the NBU. The inner glass walls of the breastfeeding room, room 15, was covered by a pinkish light curtain that had very warm coloured cartoon prints. On the concrete outer wall of this breastfeeding room was a kangaroo mother care poster. Arranged neatly in this room were fancy wooden chairs and two couches. This room was the designated space for mothers of stable babies born in the hospital to breastfeed. Mothers who still could not breastfeed expressed milk in this room. Nurses rarely came in, it was always used just by the mothers and on a few occasions, if a mother was alone breastfeeding, she would be joined by her spouse. I saw this room as the "mothers' space" parallel to KMC room in Kijani, a place where they would share experiences, encourage one another and even have a laugh.

The first door to the right immediately by the entrance to the NBU was the linen store, room 2. In this room, clean/fresh linen for the cots and gowns for the neonates were neatly arranged. Unlike in Kijani hospital, all the neonates in Tausi would have their linen and white gowns changed every morning after bathing. Adjacent to the linen room is a pantry, room 5. In the pantry, there was a white fridge for storage of expressed breast milk. Mothers here either expressed milk into cups or used their own breast pumps after which they transferred the milk into their labelled bottles stored in the fridge available in the pantry. On top of the fridge were paper towels for use by both the staff and mothers. There was a sink for cleaning the feeding bottles. Nurses would also use this sink to wash their cups. Babies in Tausi hospital whose mothers had been discharged were either bottle-fed or NG tube fed in case their mothers were not present during feeding times. My observations showed that mixed feeding was practised here which was not the case in Kijani. Often parents would buy a tin of formula milk and also provide expressed breast milk. Formula milk was given to the baby when the expressed breast milk had run out. As, in room 16, cold running water from

the taps was always available. There was a hot water kettle for boiling water in the pantry. Placed on the sink in the pantry in the NBU was a dispenser of liquid soap. On the surface by the sink were buckets, each labelled with the respective baby's name. The mothers would wash their own breastfeeding pumps and bottles before refilling. The nurses would wash the feeding bottles after they fed the babies in the absence of the mothers.

At admission, Tausi parents were asked by the nurses to buy a bucket and feeding bottles, as these were not available in the hospital. Underneath the sink was a dustbin where pieces of gauze used in washing the bottles were disposed of. In this room, there was also a metal cabinet that was used as storage space for unused files and other documentation material. Like in Kijani, mothers never ate in the NBU. Those admitted would take tea and meals provided in their rooms. Those who had been discharged would eat in the restaurant on the ground floor. Others would carry food from home and eat in the lounge outside the NBU. The hospital did provide tea for the nurses but it was served in a staff common pantry outside the NBU and the NBU nurses did not like going there for their tea as they felt it was crowded and "far". Though not allowed, nurses would boil water using the electric kettle in the pantry and prepare their own cup of tea which they would drink stealthily at the nurses' station in the NBU as they feared their superiors walking in and finding them enjoying a cup of tea while in the NBU.

The NBU had two rooms for premature babies right next to each other, each clearly marked premature units 1 and 2; room numbers 6 and 7 (see figure 5.6). These premature units each had one incubator which was never shared and a chair for the mother. Mothers could use this chair for KMC. Unlike in Kijani, intermittent, two hours of KMC was practiced during the day. Tausi hospital did not have designated KMC rooms, therefore mothers whose babies required KMC did so intermittently while sat on chairs right next to their baby's incubator. Further, Tausi NBU did not have champion mothers to offer advice and KMC support to fellow mothers as the case was in Kijani, formal support was provided by the nurses. Next to the premature units is the Neonatal Intensive Care Unit (NICU) room 8, where very sick babies are placed. A red drug cabinet was always permanently placed in the NICU. Among the equipment in the NICU was one incubator, one radiant warmer, two oxygen cylinders, one suction machine and a continuous positive airway pressure machine (CPAP). There was a big window which always remained closed. The NICU also had a couch that was often used by the nurses, however, parents visiting their baby in the NICU could also sit on this couch. There was also a stool and a small table that was used by the nurses caring for the babies in the NICU. Placed on this table were the treatment files and nurses' kardex for the

babies in the NICU. The maximum number of babies that would be cared for in the NICU at any given time was two, and each baby had their own designated nurse. As mothers with babies in NICU were mostly not admitted in the hospital, they would come in during the day for some hours, visit their newborns and then sit either in the lobby or, if they were allowed to feed, in the breastfeeding room where they would also express milk for their babies and store in their labelled bottles in the fridge.

Stationed in the open space outside the NICU, room 8, was the observation area which was adjacent to a large window. There were two radiant warmers in the observation area. Next to one of these beds was a CPAP machine. To the left of the observation area was the isolation unit, room 10. As was the case in Kijani hospital, babies referred to the facility from other hospitals were cared for in the isolation room. In the isolation room, was a radiant warmer, four cots, and four incubators and one phototherapy machine. There were also chairs for the mothers who had babies in the isolation room. Mothers with babies in isolation room would breastfeed in here, rarely mixing with other mothers in the unit. Right outside the entrance to the isolation room was the nurses' station. Nurses caring for babies in the premature units, observation area, isolation area, and the general ward sat in this space facing the room where premature babies were cared for. It is here that all the files, documentation and units' desk and unit's mobile phone were placed.

The last section of the unit which is located behind the nurses' station and adjacent to the isolation room was the general ward, room 11. The general ward housed more stable babies requiring incubator and cot care. There were 4 cots, 6 incubators, phototherapy section-rooms 12 and 13 that were specific to phototherapy- and 1 resuscitator in the general ward. There were chairs for the mothers, where they could sit during top tailing. This room was mainly busy in the mornings during top tailing when mothers and nurses would top tail the newborns. Room heaters were distributed throughout the NBU. Colourful prints of cartoon figures were mounted on the inner glass walls adding to the warmth and brightness of this NBU. The rooms had clean tiled floors and were well lit. This NBU was clean; a cleaner would mop the floor at least three times a day. The surfaces would be meticulously cleaned daily each morning and all the incubators were cleaned daily by a health care assistant. The procedure for handling dead babies in Tausi differed from that in Kijani. Unlike in Kijani where they were placed on a cot in room B for some time, in Tausi, once the parents had been notified the dead babies would be moved much faster to the hospital morgue. Just as it was in Kijani Hospital, the death of a baby in this NBU often introduced a somber and sad mood among the Tausi mothers.



#### **5.4 Organisation; Workload and cost of care**

Kijani, being a major public hospital in Nairobi, is busier than Tausi hospital with new inpatient admissions of sick newborns taking place daily. For the period between 1<sup>st</sup> July 2014 to 30<sup>th</sup> June 2015<sup>5</sup>, there were 1006 newborn inpatient admissions to Kijani which accounted for 6.8% of the total newborn patient admissions across Nairobi City County while 106 newborns were admitted to Tausi over the same period accounting for 1.1% of the total newborn inpatient admissions over the same period. (*figure 5.7*). The annual figures for 2017 – 2018 (the period of my study) are considerably lower in Kijani and higher in Tausi; this is likely primarily due to the fact that this period, coincided with a 6 months nationwide strike of public sector nurses resulting in the closure of the NBU wards in Kijani between June and November 2017 (G. Irimu et al., 2018). This impact can be seen in the monthly inpatient admissions for May 2017 to April 2018 (*figure 5.8*) where there were no admissions to Kijani, and at the same time, there was an increase in Tausi. It is likely that some of the patients that would have been going to Kijani ended up in Tausi.

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<sup>5</sup> Source Nairobi Newborn Study (NNS) study 2014/2015 data. NNS the main study within which this study is nested collected admission data only over this one-year period and thus the lack of admission data for 2015/2016.

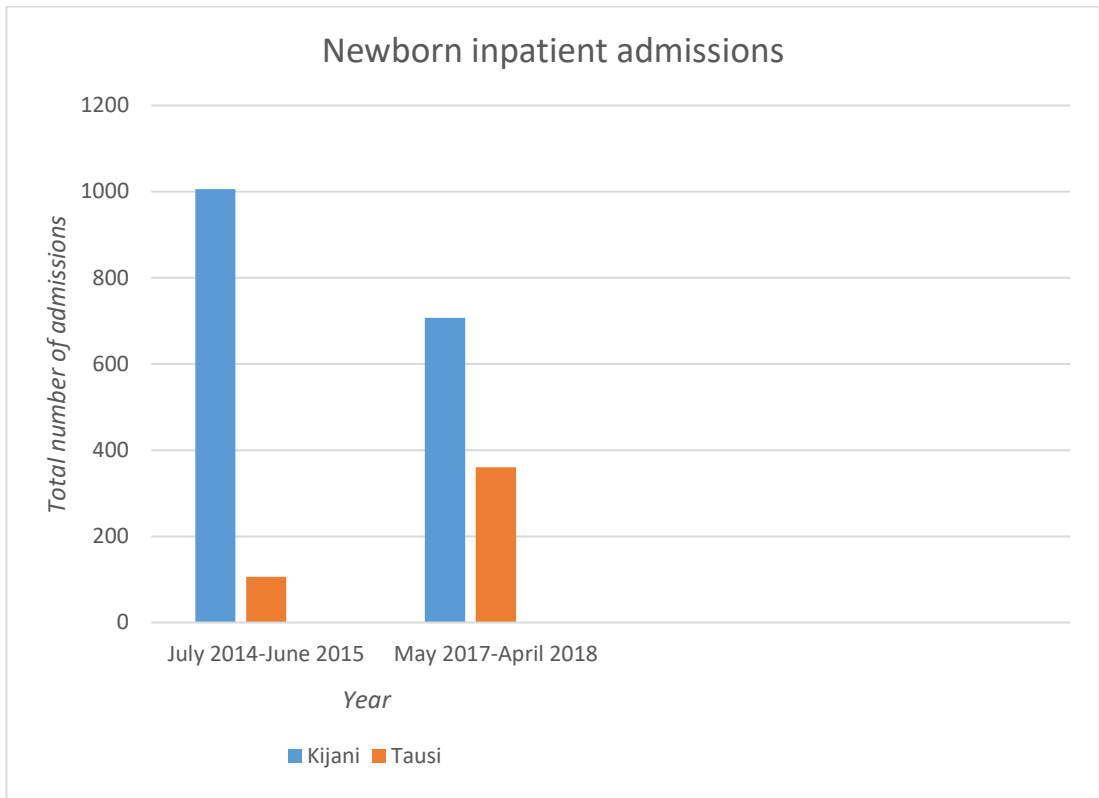


Figure 5. 5 Annual newborn admissions in Kijani and Tausi

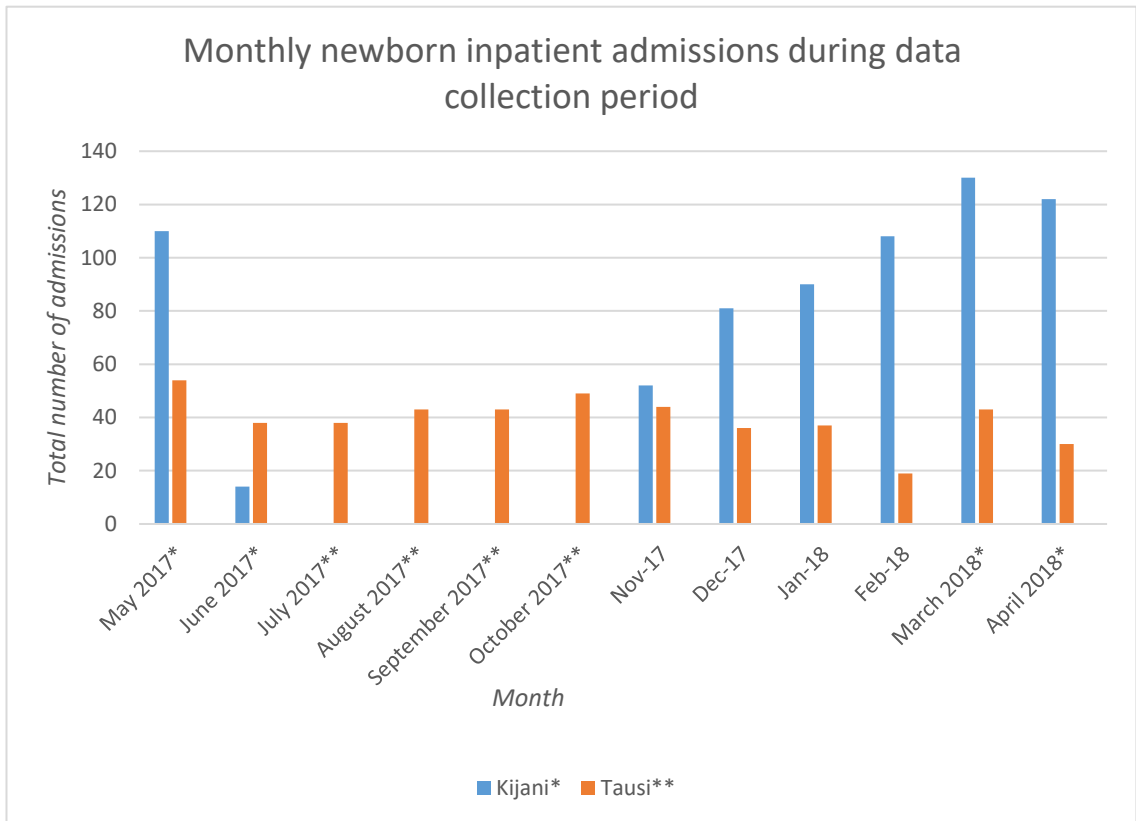


Figure 5. 6 Monthly newborn admissions in Kijani and Tausi during the data collection period

For the period Jul 2014-Jun 2015, the median length of stay for sick newborns in Kijani hospital was 5 days (interquartile range (IQR): 2-9 days) compared to a median length of stay of 4 days (interquartile range (IQR): 3-5 days) in Tausi hospital<sup>6</sup>.

Despite the availability of free services in public hospitals, mothers in Kijani hospital were seen to incur out of pocket expenditures. These included purchasing prescribed drugs if they were not available in the hospital pharmacy and paying for certain laboratory investigations and electrocardiogram tests that were not available in the facility. It was clear in my observations that referral for admission and unavailable investigations was often made to the main national referral hospital for these investigations and tests and the mothers had to bear the cost of these tests. In case of referrals of very sick newborns requiring specialised care, ambulance services were offered free of charge. Mothers unable to afford such out of pocket expenses were eligible to receive help through the hospital social services office. But this took time and contributed to delayed investigations and treatment, as the mothers would approach the staff who would then facilitate the process of requesting help from the social services department.

All the mothers whose babies were admitted into the NBU in Kijani hospital were expected to stay in the hospital throughout their babies' admission period. They were housed in the postnatal ward at no cost. Similarly, all mothers admitted into the maternity ward for delivery and postnatal ward of Kijani hospital did not incur any cost as these services are offered free of charge.

In Tausi hospital, none of the services is free. At admission to the NBU, a deposit of approximately USD 300 was required and this money needed to be paid before any treatment began. Nurses insisted that this deposit be paid before "opening of a file" (registration of the baby). In addition to the cost of the deposit, the daily cost of admission for bed, cot and treatment ranged from a minimum of USD 35 to a maximum USD 150. The cost of treatment varied depending on the recommended care for the individual baby. The cost of an ambulance in case of referral was also met by the parents. Some of these babies requiring more specialised care were from Tausi were also referred to the national referral hospital. In addition to this, there was also the daily doctor's fee which depended on the doctor treating the baby. Different doctors charged different fees ranging between USD 20-35 per day. On occasions while I sat with the mothers in the breastfeeding room, many of them complained

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<sup>6</sup> Source NNS study 2014/2015 data. NNS the main study within which this study is nested collected admission data only over this one-year period and thus the lack of admission data for 2015/2016.

about the cost of these doctor fees. They questioned why they had to pay so much to a doctor who, according to them, only came in for less than five minutes to review a baby. They felt the fee was exorbitant, as illustrated by the excerpt below from my field notes of a conversation I had with one of the mothers in the breastfeeding room:

*I almost got a shock when I saw my bill, ehh, I want him to discharge us, he comes here for just two minutes to see the baby, each time he comes, that is 2,000 shillings, eh, no! I want to go home, and he doesn't even do much, just looking and asking how he is doing and writing on the file, mhh, I want to go home, that 2,000 shillings is enough to buy me a meal at home", she laughs. (Field notes\_Tausi hospital)*

In cases where the mothers were also admitted in the postnatal ward or voluntarily opted to stay in the hospital during their baby's admission, the daily rate for their bed was approximately USD 35. To reduce hospital bills, on various occasions mothers opted for discharge and would commute daily from home to visit their sick newborn. While in Tausi hospital, almost all the families had a medical insurance cover that covered the cost of admission there was concern about the annual cap, especially where the insurance was offered by their employers. Most of the mothers were concerned about exceeding this cap as future medical costs would have to be paid for in cash/out of pocket.

## **5.5 Organization of care delivery**

### **5.5.1: The trajectory of care**

In both hospitals, at admission and through their inpatient journey, newborns were categorised and separated according to their condition/severity and place of delivery. This is outlined in Figure 5.9.

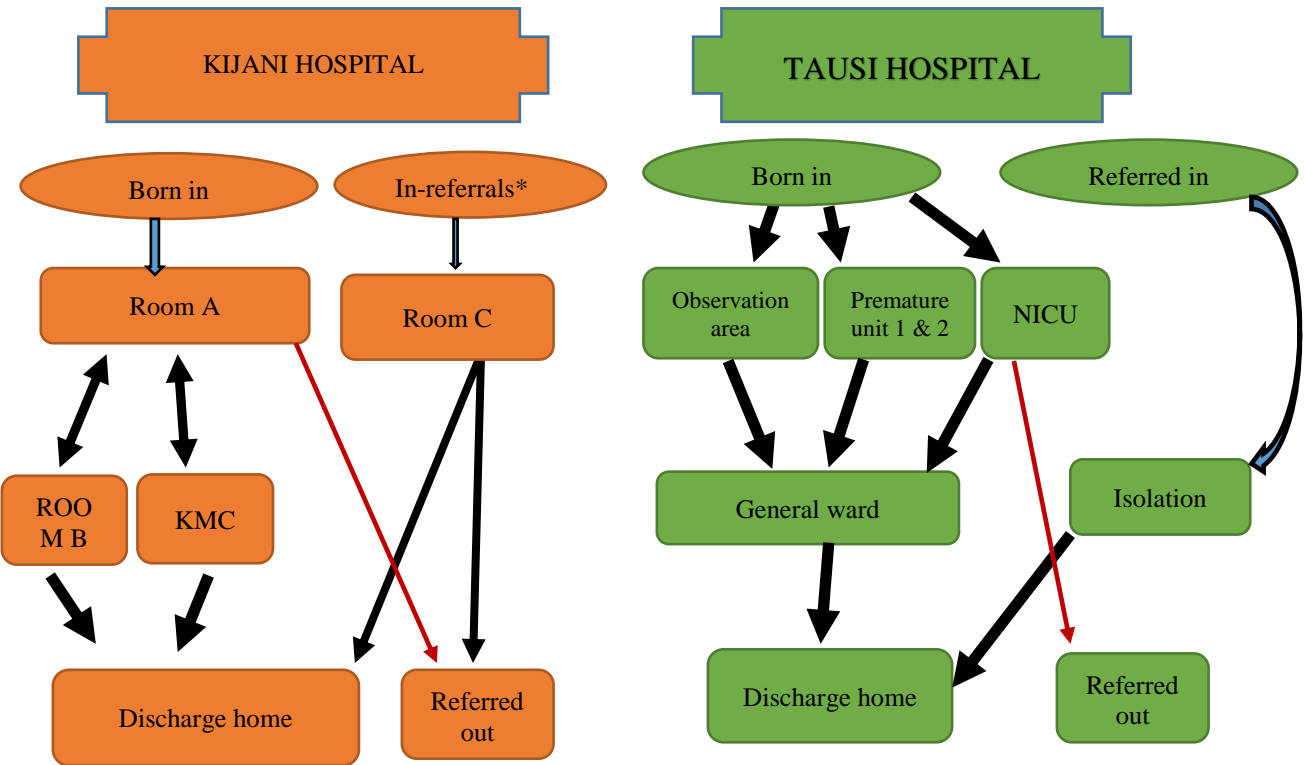


Figure 5. 7 Trajectory per study hospital

\* Babies born outside the hospital

**Kijani Hospital**

On admission, babies were received by the nurse on duty, clerked in and then reviewed by a doctor. All newborns born in the hospital and requiring inpatient admission were initially placed in room A. There was no observation area nor the practice of placing new admissions on observation for two hours as the case was in Tausi, new admissions would immediately be allocated to an incubator or placed on the radiant warmer if very sick. The babies would stay in this room until their condition improved and they no longer required oxygen or incubator care. This decision was made by the clinical team during the daily morning ward rounds. During my fieldwork, babies stayed in room A for anything between two days to four weeks. There were at least two deaths every week. Following stabilisation there were three common trajectories of care:

- i) Premature sick babies move from room A to the kangaroo mother care (KMC) room
- ii) Term sick babies move from room A then room B,

- iii) In-referrals- move from room C to home, however very sick babies from room C would at times be moved to A due to lack of equipment in room C.

Since the conditions of neonates could change very rapidly and drastically, this trajectory was not linear as babies who had been moved from A to either B or KMC could be moved back to room A upon review by a nurse, clinical officer or a doctor.

### **Tausi Hospital**

If the babies brought in from the maternity wards were not very sick, they would initially be placed in the observation area for about two hours where they would be reviewed by the admitting doctor. If admission was required, they would be moved to the general ward for treatment (sick term babies were cared for in the general ward). Very sick babies would automatically be taken to the NICU and when stabilized they would be moved to the general ward. Premature babies would be cared for in the premature unit. The hospital had two similar rooms designated for premature newborns, as described in section 5.3.2. The general trajectory of the babies in Tausi is illustrated in figure 5.9

In both hospitals, babies referred to the facility were isolated. Most of the babies in isolation were on incubators on oxygen and some on phototherapy. Tausi hospital did not have a designated KMC area, therefore mothers of premature babies do intermittent skin-to-skin contact on a chair right next to their babies' incubator or cot.

#### **5.5.2 Staffing and shifts**

Both hospitals had a consultant paediatrician. The consultant in Kijani hospital was present during major ward rounds that were scheduled twice a week or when called in to review a very sick baby. In Tausi the resident paediatrician was present daily. Additionally, Kijani hospital had a fulltime medical officer who would be on duty daily. However, in Kijani hospital all the babies were treated only by the hospital doctors, whereas in Tausi, babies could have their own private paediatricians from outside-with admission rights in the hospital. In this mission hospital, those who did not have their own paediatrician were treated by the hospital's consultant paediatrician. In Kijani hospital, on the days outside the weekly major ward rounds, the newborns admitted to the unit were reviewed by a medical officer together with the clinical officer interns and medical officer interns. In Kijani hospital nurses would rarely be part of the ward rounds, whereas in Tausi hospital a nurse would always accompany the paediatrician when reviewing a baby.

## Kijani hospital

The nurse to newborn ratio was markedly different in Kijani and Tausi hospitals. In Kijani often one nurse could be caring for 15-40 newborns during any given shift compared to a nurse to newborn ratio of 1:1 for NICU and a maximum of 1:4 for stable babies in Tausi hospital. Kijani hospital has a total of 12 nurses assigned to work in the newborn unit and to cover all of the shifts for the entire week. These 12 nurses were each assigned shifts by the nurse in charge of the unit. I observed that not all the nurses were on duty daily, a day could have an allocation of 3-4 nurses covering the different shifts. My informal discussions with the nurses working in the unit revealed there were three official shifts per day in Kijani hospital: morning shift which begins from 7:30 am to 4:30 pm; an afternoon shift which runs from 1:00 pm to 6:30 pm; and the night shift which runs from 6:30 pm to 7:30 am.

Table 5. 2 Staffing levels in study facilities

Staffing on:	Weekday Day	Night	Weekend Day	Night
<b>Kijani public hospital</b>				
Nurses	3-4	1	3	1
Clinical officer interns	2-4	0	0	0
Medical officers	1	1 ( <i>on call for multiple areas in the hospital</i> )	1	1 ( <i>on call for multiple areas in the hospital</i> )
Medical officer interns	2	1 (on call)	2	1 (on call)
Nutrition officer interns	2-4	0	0	0
Health care assistant	0	0	0	0
Subordinate staff	1	0	1	0
<b>Tausi mission hospital</b>				
Nurses	3-4	3-4	3-4	3-4
Clinical officers	0	0	0	0
Medical officers	1 (+2 on call)	1(+2 on call)	1(+2 on call)	1(+2 on call)
Medical officer interns	0	0	0	0
Nutrition officer interns	0	0	0	0
Health care assistant	1	0	1	0
Subordinate staff	1	1	1	1

During most of the shifts in Kijani, I observed, two nurses would care for the newborns during the morning shift, although in a few instances there was only one nurse on this shift. The nurse in-charge would also be present only during the morning shifts though she would mainly be handling administrative duties. The morning shift is the busiest with ward rounds, administration of medication, weighing, top tailing/bathing, feeding, referrals, and admissions happening. In most cases, the afternoon shifts only had one nurse on duty with main activities being the administration of medication, feeding, referrals, admissions, and discharges (Nzinga et al., 2019). The night shift was the longest shift in a day and only one nurse was usually assigned to this shift. On each shift, the number of inpatients in the NBU could range from a minimum of 15 to over 30 babies. Kijani hospital is one of the institutions where nursing students drawn from the various nursing colleges within Nairobi as well as clinical officers' interns gain hands-on experience during their training.

Observations in this public hospital revealed that care was provided by the student nurses, clinical officer interns and nutrition interns who worked only on weekdays from 8:00 am to 5:00 pm under supervision of the nurses, medical officer, and hospital nutritionist respectively. There was one subordinate staff member assigned to the newborn unit whose roles were cleaning of the floor, transferring the dirty linen to the laundry and bringing fresh linen back. She would also clean the incubators, though not daily, and provide the mothers with hot water for top-tailing. She would fetch the hot water from the urn in the nurses' office and transfer onto the small top tailing basins that were kept in the cup washing room. The hot water was mainly provided in the morning. This member of subordinate staff worked seven days a week. She only worked during the day.

### **Tausi**

Tausi mission hospital also has a total of 12 nurses assigned to work in the newborn unit. These 12 nurses were each assigned shifts by the nurse in charge of the unit. Not all the nurses were on duty daily, a day could have an allocation of 3-4 nurses covering the different shifts. There are two 12 hour shifts in a day in Tausi, day and night shift. The day shift runs from 7:30 am to 7:30 pm, the night shift starts from 7:30 pm to 7:30 am. Only two nurses in the NBU are trained on intensive care and therefore these two were mostly assigned to care for babies in the NICU, they would only cover one 12-hour shift, this was not the case in Kijani where none of the nurses had received any specialized intensive care training and therefore any nurse assigned to work on the NBU cared for all categories of babies. In instances where there were two babies in the NICU, locum nurses either from the hospital ICU or one other on locum who also works in the national referral hospital were assigned to



care for the critical babies during the second 12-hour shift. Thus at all times, babies in the NICU had 1:1 care. Apart from the nurses and the doctors, there is a health care assistant assigned permanently to the NBU. Her roles mainly are daily dusting and cleaning of the incubators and surfaces, clerical duties such as collecting supplies from the pharmacy, store, taking files to the accounts and back. Cleaning of the floors and windows was done by a member of subordinate staff. Unlike in Kijani, Tausi hospital did not have any nursing students or interns working on the NBU.

Table 5.3 presents the number of nurses for both day and night shifts vs the maximum number of daily inpatient admissions over the period of data collection in each hospital.

Table 5. 3 Number of nurses' vs total inpatient admissions per shift

	Day		Night	
	<i>Nurse</i> <i>(n=3*-</i> <i>including nurse</i> <i>in-charge)</i>	<i>Babies</i> <i>(n=41)</i>	<i>Nurse</i> <i>(n=1)</i>	<i>Babies</i> <i>(n=41)</i>
<b>Kijani</b>	2 <i>(covering entire</i> <i>NBU)</i>	8 in room A 15 in room B 5 in room C 13 in KMC	1 <i>(covering entire</i> <i>NBU)</i>	8 in room A 15 in room B 5 in room C 13 in KMC
	Day		Night	
	<i>Nurse</i> <i>(n=4)</i>	<i>Babies</i> <i>(n=12)</i>	<i>Nurse</i> <i>(n=4)</i>	<i>Babies</i> <i>(n=12)</i>
<b>Tausi</b>	2 <i>(covering NICU)</i>	2 in NICU	2 <i>(covering NICU)</i>	2 in NICU
	2 <i>(covering</i> <i>premature unit,</i> <i>Isolation and</i> <i>general ward)</i>	2 in premature unit	2 <i>(covering</i> <i>premature unit,</i> <i>Isolation and</i> <i>general ward)</i>	2 in premature unit
		1 in isolation		1 in isolation
		7 in general ward		7 in general ward

## 5.6 Summary and discussion

In this chapter, I have provided a description of the two hospitals and NBUs that were involved in the study. Despite their proximity to each other in Nairobi, the two hospitals were strikingly different in their staffing levels, infrastructure, available space, amount of

equipment, and general physical and social environment. The difference between the two hospitals in their nurse staffing levels, the availability of medicals officers and paediatricians and available infrastructure, suggests considerable inequity between the mother's ability to access appropriate and timely care within Nairobi.

Many studies undertaken in neonatal units in HICs have found that staffing ratios impact the quality care provided (Mefford & Alligood, 2011; Rochefort & Clarke, 2010; Tubbs-Cooley, Pickler, Mark, & Carle, 2015; Tucker, 2002). In the UK, the minimum standards for nurse staffing levels for each category of neonatal care are 1:1 for neonatal intensive care, 1:2 for neonatal high dependency care and 1:4 for neonatal special care (NHS, 2018). Similar standards are found in the European standards of care for newborn health, with a recommended ratio of 1:1 for the very sick/critical babies and a ratio of 1:2 for relatively stable babies (Poets CF, 2018). These ratios are in stark contrast to the ratios of 1:4 for the very sick babies and a minimum of 1:12 for the stable babies that I often observed in Kijani and 1:1 for the very sick babies and 1:4 for the stable babies in Tausi. These findings are not particularly surprising in light of a recent study of neonatal nursing conducted across 33 hospitals in Nairobi which found a high nurse to patient ratios of 7-15 patients per nurse (G. Murphy et al., 2018); or the findings of a recent analysis of factors influencing the delivery of quality newborn care in 12 countries in Africa and Asia which found that shortages of neonatal nurses was a key problem (Moxon et al., 2015). The disparities presented in this chapter, in conjunction with these wider ratios, point to significant inequity within neonatal care in urban Nairobi in addition to the evident inequity between neonatal care in public hospitals in Kenya and other LMICs and those in HICs.

Within Nairobi, these inequities are further made evident in this study through the overcrowding in Kijani compared to Tausi. In Kijani, babies shared incubators and mothers shared beds whereas in Tausi babies never shared incubators and mothers had their own beds or own private rooms. Understaffing and overcrowding in neonatal units have been shown to be linked to recurrent outbreaks of infection (Fischer et al., 2019; Haley, 1982). The overcrowding observed in Kijani is potentially putting these already highly vulnerable neonates at higher risk of infection than the neonates in Tausi or those in better-resourced settings.

A further clearly noticeable difference between the two hospitals was the general atmosphere within each hospital. Kijani hospital, and the NBU, in particular, was noisy and overcrowded. The ward had an air of neglect. It was stuffy, had inconsistent water supply

and at times tanks overflowed, and there was a shortage of linen and gowns for both the mothers and babies. This was in contrast to Tausi which, in general, was calm and quiet, had a nice smell and working facilities as well as an adequate daily supply of clean linen and gowns. Several studies in HICs have shown that the care environment and nurses' satisfaction with their environment can impact health outcomes (Aiken et al., 2011; Cho, Lee, et al., 2016). Furthermore, the amount of attention paid to the environment in which care is provided could be seen as a reflection of how the patients (and staff) are viewed by the hospital management and broader society.

The women in Tausi are 'paying customers' who have the social and economic capital to allow them to make choices about where they give birth. In Kijani, by contrast, the women have little social or economic capital constraining their choices over where they deliver their baby. It could be argued that the visible neglect of the environment in Kijani mirrors the relative and 'hidden neglect' of these women by the hospital management, broader Kenya society, and the global health community; evidence of structural violence in action affecting the lives of the Kijani mothers and the health outcomes of their babies. These findings are hardly new, Sharma and colleagues in their study on inequities in the quality of maternal health care in Kenya found similar results (Sharma et al 2017). They concluded that the quality of care for the poorest women is significantly less than that available to the least poor women, although overall quality in Kenya was low (Sharma, Leslie, Kundu, & Kruk, 2017). These findings are also in line with those of several other studies conducted in LMICs (Kruk et al., 2016) demonstrating that the vulnerability of mothers and their babies is shaped by broader political, social and economic forces.

Interestingly, while the ward environment in Kijani was neglected, the KMC rooms were clean and bright and un-crowded, this 'good' environment being facilitated by external donor funds, specific to that intervention. While good for the mothers in KMC, the existence of these spaces does create the stark contrast of a vertical (aid) programme creating a very limited and potentially unsustainable improvement without addressing the underlying systems and structural issues that create vulnerability in the mother and infant.

The differences between the women in Kijani and Tausi, in general, were also made visible by the way the mothers were treated by frontline staff and the hospital management. Dead babies left on the cots in Kijani and a lack of attention paid to the effect that this was having on the mothers is a sign of neglect of the mother's needs. Additionally, in Kijani the practise was that nurses never shared shoe racks and avoided sitting on the plastic chairs used by the

mothers in the ward. These actions, in sharp contrast to the treatment of the mothers by the nurses in Tausi (sharing the shoe rack and seats), is a stark indication of the social gulf that appears to separate many of the nurses in Kijani from most of the mothers and a reflection of how the mothers in Kijani are perceived by many of the nurses. These findings on the neglect and the social inequities that women face are in line with findings reported by studies on respectful maternity care (RMC). Reported in these studies, are mistreatment (Bohren et al., 2017; Bohren et al., 2016; Sheferaw et al., 2017; Warren et al., 2017), neglect of the environment (Balde et al., 2017; Kambala et al., 2017), poor relationships between mothers and providers (Rominski, Lori, Nakua, Dzomeku, & Moyer, 2017; Sheferaw et al., 2017) all of which not only contribute to the violations of the rights of these women but could also deter utilization.

The picture painted by my observations of the mothers with sick babies in Kijani and Tausi suggests that there are considerable inequities within Nairobi in the care that women and their sick newborns have access to. The women of Kijani who have little social and economic power (economic and social capital) are most at risk of the structural violence that curtails access to respectful and quality neonatal care. These observations are not unique but rather add to a growing body of literature not just on the inequities in maternity care provision between HICs and LMICs but also within LMICs alongside the broader growth in economic inequity within populations (Wirth et al., 2008).

In this chapter, the data have suggested that the social and economic status of the Kijani women makes them more vulnerable than the mothers in Tausi. However, during my observations I noted that there were indications that despite the difficult environment, facing the mothers in Kijani, they were adopting strategies, for example sharing of linen and other support, to help them cope with the lack of resources and other challenges. These issues will be investigated further in the next chapters.

## **6. RESULTS 2: BECOMING A MOTHER; MOTHERS' PRACTICES AND RELATIONSHIPS WITHIN THE STUDY NBUs.**

### **6.1 Introduction**

In this and the next results chapter, I will focus on providing a description of the experiences of the mothers whose babies are admitted to the NBU in Kijani and Tausi hospital. In this chapter, I concentrate on describing the daily lives of these mothers while their babies are inpatients on the NBU wards. I describe the involvement of the mothers in providing care for their babies, describing the tasks that they undertake, and how they are introduced to and are prepared for these tasks. I describe their practices and discuss their feelings towards their involvement in care. Further, I explore in greater detail the relationships among the mothers and between the mothers and the nurses within the NBU, with a focus on how these relationships facilitate or hinder the day to day practices of care undertaken by the mothers. For this chapter, I draw on data collected through the non-participant observations and discharge interviews, reflecting on my own perceptions and views as well as those of the mothers. Having described the context of newborn care in both study hospitals (in chapter 5) and critically assessed the differences in structures, artefacts and organizations between the two hospitals, I now explore how the nature and extent of the mother's involvement in caring for their newborn and their day to day experiences are shaped by those contexts. I structure this chapter along the lines of the trajectory of care for infants within the NBUs from admission to point of discharge (see chapter 5 figure 5.9).

The chapter is divided into five sections as follows:

- Section 6.2 describes the types of mothers whose babies were admitted to the NBU during the period of study.
- Section 6.3 describes events that transpire within the first 24 hours of a baby's admission onto the NBU, the involvement of mothers in these events and their role in various activities.
- Section 6.4 outlines the activities that mothers are involved in after the first 24 hours of their baby's admission. This section is divided into two sub-sections:
- Section 6.4.1 and 6.4.2 provide a description of the tasks undertaken and the mothers' feelings about their involvement in care when their babies are critically sick. In these sub-sections, I also examine the existing relationships within the two study sites and investigate how different relationships interplay to impact on the mothers' learning and role acquisition.

- Section 6.5 provides a description of the tasks that mothers continue to play as their babies' transition into the stable phase and their feelings towards performing these tasks. I continue to explore the relationships between the different actors and how these relate to the role acquisition process.
- Section 6.6 provides a discussion of the findings, focusing on the similarities and differences between the two study hospitals with regards to the tasks, roles, feelings, and relationships. I also discuss some of the possible implications that these context-specific ways of involvement may have on strategies for improving the quality of newborn care in NBUs.

## **6.2 Types of mothers**

As mentioned in chapter 5, these two hospitals cater for different clientele; mothers found in Kijani public hospital were mainly of low socio-economic status and were either unemployed or in the informal job sector, this data is recorded in the mothers' files and reflects the socio-demographic data of the mothers whom I interviewed at discharge (*see table 6.1*). The age range of the mothers varied in both facilities from 14 years to 40s, however, mothers in Kijani appeared younger in comparison to those in Tausi mission hospital. In the public hospital, mothers mostly spoke in Kiswahili or in their mother tongue while those in the mission hospital would rarely speak in their mother tongues, the most commonly used languages were Kiswahili or English. In both hospitals, there was a mix of both married and unmarried women.

This sub-sample is representative of the population across the two study sites. I collected the socio-demographic data presented below from all the women interviewed at discharge.

Table 6. 1 Socio-demographic representation of the mothers in the two study hospitals

Variable	Classification	Kijani (n=20)	Tausi (n=20)
Age (Years)	Below 20	2	0
	20-25	6	6
	26-30	8	7
	31-35	1	4
	>35	3	3
Education	None	1	0
	Primary	7	0
	Secondary	10	1
	Tertiary	2	19
Occupation	Unemployed	8	3
	Casual*	4	0
	Semi-skilled**	7	0
	Employed***	1	17
	Other	0	0
Marital status	Single	6	2
	Married	14	18
Number of children	1	5	12
	2	7	7
	>3	8	1

*Casual\* Lack of any tertiary skills training*

*Semi-skilled\*\* Possess minimal skills training*

*Employed\*\*\*Posses extensive skills training and are mostly informal employment*

Most of the mothers interviewed at discharge from both hospitals had at least secondary education but while the majority of women who had given birth in Tausi had received tertiary education this was not the case for the women who gave birth in Kijani. The other key difference between the women from the two hospitals was that many of the women from Tausi had full-time employment whereas most of the women in Kijani were either unemployed or employed in semi-skilled or casual positions. The median length of stay for a sick newborn in the newborn unit at Kijani was 5 days while that of newborns admitted in Tausi hospital was 4 days.

### **6.3 The first 24 hours; birth and admission onto the NBU.**

In both Kijani and Tausi, the premature and sick babies born within the hospital were transferred within the first 24 hours of birth from the maternity ward to the NBU for specialised care. The transfer of a baby from maternity to the NBU was an important transition point for a mother, often marked by shock and confusion. As illustrated by the

quote below, this initial 24-hour period was emotionally charged with a mother's main concern being to try to understand what was going on, both in terms of the baby's condition (how critical and the likely outcome) as well as the process – where the baby was being taken, by who and what they should do. These fears and concerns are discussed further in chapter 7.

*“After the baby was removed, I just heard the... okay could uhh hear some movements because they had that curtain so when they removed the baby, I heard the cry, then they just carried the baby to a certain place, I could see everything with the baby and my paediatrician was like struggling because the baby could not breathe. He had to spray some things then the mask the everything he struggled and struggled and I was now “Gosh, will this baby survive?” those were the questions that were in my head. I was confused and I, .... the baby was brought to the nursery [NBU] then I had to wait for uhh I was taken to the recovery room and then later ward”. (DI\_T014)*

While some mothers had been able to anticipate their baby's arrival, for other mothers the birth had been a shock. Mothers' journeys were different from the start, as their involvement in care varied between hospitals. While in Tausi hospital all babies requiring admission were transferred by a nurse, in Kijani hospital this varied. In Kijani, critically sick babies were transferred by a nurse and the more stable ones were carried by their mothers. To illustrate how events generally unfolded in the two study hospitals, I now relate the story of what happens immediately following delivery.

### 6.3.1 Mothers' initial hours in the NBU

The two study hospitals presented two diverse contexts where there were stark differences in the experiences of the mothers during the first 24 hours of their baby's admissions.

#### **Kijani**

In Kijani hospital, mothers were involved in caring for their newborns within the first 24 hours of delivery. While some mothers had experienced a trouble-free delivery, others had had some kind of complication, such as extremely high blood pressure, prolonged labour or other conditions that necessitated delivery via caesarean section. The mothers who had a trouble-free birth were well enough to walk up to the NBU either on their own or accompanied by a nurse and become immediately involved in providing care for their babies. For mothers who had complications (who had undergone surgery or were still themselves



receiving treatment in the maternity ward), their arrival in the NBU was delayed. The focus for subsequent descriptions in this chapter is on those mothers who were well enough to start caring for their babies within 24 hours of delivery.

The level of care that these mothers were able to provide in the first 24 hours was influenced by how well or sick their newborn was. An example of the experience for mothers with very sick babies that required medical oxygen during the first 24 hours of admission is provided in box A. The observed experience of a mother with a premature baby that didn't require oxygen is described in box B.

As is described in the boxes, within the first 24 hours of their baby's admission, mothers, even of babies that needed to be placed in a resuscitator, would become involved in providing some level of care. For all babies, the main task performed by the mothers during the first 24 hours of admission in Kijani was diaper changing and for those who were not on the resuscitator, feeding. Though there were a few who breastfed term babies with jaundice or an infection, mothers of premature babies who were not on oxygen therapy expressed milk and NG tube fed their babies. In very rare instances, the mothers would also top tail (clean) their baby but this would depend on the timing of admission. As described in chapter 5, hot water for top tailing was provided once a day at 6.30 in the morning, therefore babies admitted after 7 am or at night were not top tailed until the following day. Throughout the first 24 hours of admission, the nurses on the ward concentrated on giving medication while the mothers took up the bedside monitoring and care of their babies. As described in boxes A and B at admission, I observed that after receiving the baby and the baby's notes from the maternity, the nurses admitted the babies and directed the mother on where to place their baby. After admission, the nurse would fix the IV lines and NG tube as required, and then instruct the mothers on what to do. This brief exchange of information often involved the mother being directed to change diapers, express milk, and feed the babies. Following these initial actions and in between their busy routine of medication and paperwork, the nurses then conducted regular formal observation of the critical babies in the radiant warmer.

**Box A: First 24hrs in Kijani – room A**

**Multiparous mother with a very sick baby**

It's just a few minutes past eleven o'clock and the doctors and clinical officer interns have just finished conducting the morning ward rounds in room A. On duty this morning is nurse Mwajuma. Mwajuma is so engrossed with calculating the fluids and fixing the IV fluids for the 14 babies in room A she barely talks to the mothers who are expressing breast milk by their baby's incubators. As I had observed that some of these mothers struggled with expressing milk, I expected her to once in a while check on what the mothers were doing and offer assistance. Once in a while some of the mothers needing help with feeding try to catch her attention, *"let me finish with this I will come"*, she responds. She moves from one baby to the next. The room is very calm, with the mothers each sitting on a plastic chair by their baby's incubator. As they express milk, they sometimes pause and take a moment to catch a breath. Apart from complaining about the pain, some of the mothers talk amongst themselves about how difficult and tiring expressing milk is. Once in a while they look at each other and smile, a few compare how much they are able to express. Tough as it is, they carry on till they attain the 'required' amount. During these activities, a nurse carrying a baby from the maternity ward walks in and tells Mwajuma *"this is your baby where do I place her?"*. The nurse from maternity is accompanied by the baby's mother who had delivered just within the past 30 minutes. They are followed by three other mothers, each carrying their baby. These three mothers each have a baby that is premature but stable and they are shown by Mwajuma where to place their babies. All are placed in shared incubators. For the very sick baby carried by the nurse, a brief hand over lasting about 5 minutes follows with the baby placed in a radiant warmer. Both nurses stand by the radiant warmer they hold a brief discussion with the maternity nurse briefing Mwajuma about the baby's problem. After the process of handover is complete, Mwajuma proceeds to set up the oxygen and fluids for the new admission. All this while, the baby's mother sits quietly on a plastic chair next to the table. Mwajuma had pointed to her where to sit. She is dressed in a blue hospital gown, tied around her waist is a lesa, her hair looks unkempt. Her eyes fixed on the radiant warmer where her baby is lying; she doesn't talk at all. Once the new baby is linked up to the oxygen and fluids Mwajuma briefly turns to the new mother and offers her some information, explaining: *"we will not feed her for now, she has problems breathing so for now we will put her on oxygen, we will tell you when you can start feeding"*. Mwajuma then moves on to attend to the other babies leaving the new mother sitting on the chair where, after a short while, she dozes off sitting upright. The other mothers by now have finished expressing milk and carry on with feeding their babies. Some of these mothers step out of room A after feeding their babies leaving behind the new mother and others who choose to remain behind to observe their babies after feeding. While some of these mothers chat with each other, others sit quietly just looking at their babies, once in a while getting up to gently touch their newborns [opening the incubators or through the hole in the incubator]. It is now 1:30pm, the drugs round for all the babies on the unit has finished and as Mwajuma passes by, she notices the new mother sleeping on the chair. She tells her to go back down to the postnatal ward and rest. Throughout the day, the mother occasionally pops in to check on her baby, the only task she can perform on this day is change diapers. To do this she unfastens the diaper to check if it is soiled, and if it is she proceeds to change it using the new one she brought up with her from the maternity ward. When they come to deliver, mothers bring with them essential baby items such as clothes and diapers. The information about what to carry when going to deliver is normally given to pregnant mothers at their antenatal clinic. I notice that she initially attempts the diaper change with some hesitation, she removes the straps of the diapers, takes some time looking at the baby as if wondering what to do next but eventually manages to finish the process. Taking great care not to touch the IV tube and the oxygen mask, she barely lifts the baby, gently holds up the baby's legs and lifting slightly the baby's lower torso to remove the soiled diaper and places a new one. One of the mothers then shows her which bin to throw away the soiled diaper. She then goes back to the postnatal ward. Unlike the rest of the mothers, she is still not allowed to feed. Just as it is with most of the mothers whose babies are new in the NBU, her interaction with other mothers on this first day is very minimal, only talking to them when she needs something. On this day, despite going back to rest in maternity ward, she frequently visits the NBU to check on her newborn and to change diapers.

## **Box B First 24hrs in Kijani – room A**

### **Premature baby**

Among the three other mothers whom nurse Mwajuma had shown where to place their babies was Hellen. Hellen is a first time mother and she was told to place her baby in an incubator that already contained another premature baby. For the first one hour, she mostly just stares at what is happening around her. Next to her are other mothers including the mother of the baby that is in the incubator with her baby, all of whom are busy either expressing milk or feeding. Nurse Mwajuma is still attending to the baby in the radiant warmer and Hellen appears to have no idea what is expected of her or what she is to do. She keenly observes what the other mothers are doing and strikes up a conversation with the mother of the baby who shares the incubator with her baby. Her neighbour had been there for a couple of weeks. Under each incubator are drawers and her neighbour informs her that she can keep her babies diapers and feeding cups in the drawer. After checking, Hellen realises that her baby needs a diaper change and goes down to the postnatal ward to bring some diapers, she had brought with her essential baby items such as clothes and diapers which she had left in the postnatal ward. Upon her return, she turns to one of the mothers next to her and asks how it is done, she asks how to open the incubator and how to change the diaper. Having been there for some days now, her neighbour knows how to open and close the incubator and Hellen observes and learns from her neighbour. She is instructed by the mothers next to her on how to go about diaper change and how to close the incubator when done.

Mwajuma passes by and tells her to express milk and feed the baby. *“She doesn’t have this pipe”*, she informs Mwajuma who then tells her and asks her to wait a bit. As nurse Mwajuma goes away, Hellen turns to the mother next to her and asks, *“Where do I get the cup and how do I know how much I am to feed?”* she asks her neighbour. *“The nurse will fix for you this pipe and tell you how much to feed”*, she is told. She sits and waits for Mwajuma to get to her baby. When the nurse gets to her, she stands behind the nurse wanting to observe what the nurse was doing. However, immediately she notices the NG tube being inserted in her baby’s nose, she moves back and looks the other way, with both hands on her cheek. She can’t bring herself to observe the procedure. One of the mothers next to her smiles and asks her what was wrong to which she responds that she can’t watch that pipe being fixed, she imagines that the baby is feeling pain.

After fixing the NG tube, the nurse provides her with feeding syringes and tells her *“do you have a cup, get a cup and express milk, then measure 5 mls and then feed the baby, I will get you the syringe, so you measure and then pour into this pipe”*. She is handed the syringes which she places on the drawer on her baby’s incubator and proceeds to get a cup. She is advised by the mother she is sharing the incubator with to go and buy a cup downstairs by the gate. Hellen leaves the NBU and after a few minutes she walks back in with a cup, sits back on the chair and begins expressing. Having seen what the other mothers were doing, she follows suit and does what she saw the other mothers do. Unsure of what to do next after expressing, she turns to her neighbour and asks how to measure. *“Put what you have expressed into this syringe, you see this lines and numbers here, pointing to the marks on the syringe, so this is one..two...five, so you put until here and then you open here and pour the milk inside the pipe”*. After feeding her baby she is shown where to wash her cup and she then keeps her feeding cup and syringes on her drawer. After feeding she continues to sit by her baby’s incubator talking in low tones with her neighbour.

She asks *“for how long she will have to stay in here”*. The other mothers almost in unison tell her that she will have to be patient as with such babies one can never tell for how long one will stay in the hospital. She becomes curious and asks the others for how long they had stayed there and one of the mothers tells her not to worry she will just find out as the days go by. *“does it mean that I may stay here for very long? How will I survive the way I hate the hospital environment?”* she asks, and one mother tells her that no one likes the hospital environment, *you are just forced to stay because there is nothing much one can do with a sick baby at home. “welcome to the club” another mother tells her.* She spends the whole day in the NBU following the routine that she sees the other mothers following and feeding when others are feeding.

In Kijani, despite the fact that I observed considerable anxiety among all the mothers within the first 24 hours, there was a noticeable difference in the manner in which mothers tackled the expectation of immediate involvement in their baby's care. In general, the multiparous older women appeared to cope better with these expectations. In comparison, the uncertainty of not knowing what to do appeared to complicate things for first-time mothers. The process of beginning to take on the care of their newborn was harder for the younger first-time novice mothers who did not have the practical skills acquired through previously caring for a baby. For example, diaper changing for the multiparous mothers, who already had previous experience of caring for a baby, appeared to be a straight forward compared to the first time mothers, many of whom I observed struggling with this task.

The severity of their babies' illness dictated the experiences of mothers in involvement in providing care for their newborns within the first 24 hours of admission. Just as it was for first-time mothers, the mothers of extremely premature babies also initially struggled practically, irrespective of their parity. This was clear in the manner in which they handled their newborns while changing diapers as illustrated by the passage below from my field notes. They did this very gently, occasionally pausing as they touched their newborns, some with a grimace of pain on their faces, probably indicating their fear of hurting the baby.

*"Me I have never seen something like this,"* she says as she tries to change her baby's diaper. She gently lifts the baby and places the diaper and quickly leaves it for a minute, stands back and looks at the baby with her hands placed on her cheeks. *"This is my second born, the firstborn was not like this one, I have never seen a baby this small"*, she says. She leaves the diaper without fixing the straps and walks away..... (Field notes\_Kijani hospital).

However, despite their hesitancy, the motivation to perform this task seemingly emanated from their understanding that the bedside care of their babies lays squarely with them. Learning how to undertake these tasks effectively was achieved mainly by observing what other mothers who had been in the unit longer were doing. Through these observations mothers new to the NBU were able to grasp the techniques and steps involved in providing care for their baby in this environment. When unsure, I observed mothers would often turn to their neighbours for help.

## **The first 24 hours in Tausi**

In Tausi the babies to be admitted to the NBU were always brought to the unit by a maternity nurse. At times the next of kin, in most cases the baby's father, accompanied the nurse. In contrast to Kijani, it would take several hours before the new mothers started making their way into the NBU. This was the case for all mothers irrespective of the mode of delivery and their condition at delivery. Unlike the scenario in Kijani, where the mothers (when physically able) followed or took their babies from maternity to the NBU and only subsequently found their way back to the post-natal ward, the mothers in Tausi were all transferred from the maternity ward to a room in the post-natal ward for recovery. Mothers of the babies admitted in Tausi, therefore, took much longer to come to the NBU than in Kijani. For instance, I observed that the mothers whose babies were admitted in the mornings would rarely come to the NBU during the day. Exit interviews with these mothers revealed that most of them only visited the NBU for the first time more than six hours after their baby's admission. The practical norm in Tausi had the effect of promoting mixed feeding (breastmilk and formula) among even the otherwise well but premature babies.

As discussed in chapter 5, one of the mandatory items in the list of requirements for a new parent whose baby was admitted onto the newborn unit in Tausi was formula milk. Therefore, before the mothers came to the NBU, babies were fed on formula milk and even after the mothers started visiting the NBU, babies would be given formula milk whenever a mother could not be reached or if there was no more of her expressed breast milk for her baby stored in the fridge. Babies in Tausi were bottle-fed if stable and NG tube fed if critically ill by the nurses in the absence of their mothers. I also noted that the babies' diapers were changed by the nurses during the time their mothers were absent from the ward, an activity I never saw being undertaken by nurses in Kijani except for abandoned babies. The first 24 hours for a mother whose baby was admitted to Tausi NBU are described in Box C

**Box C The first 24 hours Tausi**

Towards midday, a nurse from maternity wheels in a baby from the delivery room into the NBU. She greets Monica who is one of the three NBU nurses on duty today. Monica was sitting at the nurses' station busy catching up on paper work. The maternity nurse greets her and informs her that there is a new admission. As they walk towards the radiant warmer in the observation area where all new babies brought to the NBU are first placed, Monica the NBU nurse peruses through the file as the maternity nurse pushes the cot towards the resuscitator. After a brief hand over between the two nurses, Monica places the baby on the resuscitator and fixes the oxygen mask for the baby. The baby was having difficulty breathing.

As the maternity nurse walks out a gentleman who was the baby's father walks in carrying a bag with the baby's items. His wife had delivered via CS and was still in the maternity ward. Monica greets him and he explains that he had some items for the baby. Together with Monica they look through the bag and he is informed that the baby clothes were still not needed at this point, Monica takes out the diapers and informs him to bring formula milk, a bucket and feeding bottles for his baby. Having been directed on where he could buy the items required, he leaves.

Monica then reads through the baby's file and fixes the IV fluids for the baby. She continuously keeps an eye on the newborn. By the time we leave the NBU at the end of the observation (after 5 hours) the baby's mother had still not come to the NBU. The next morning when we return for the observations, on inquiry we are told that the mother had come to the NBU once (over the night) to check on the baby and would soon start expressing milk for the baby.

As can be seen from the descriptions in this section there were significant differences in the first 24 hours post-delivery in the activities and involvement in the care of their babies among mothers whose babies were admitted to the NBU wards in the two hospitals. These differences are summarised in figure 6.1 which illustrates the activities undertaken by mothers in the first 24 hours of their baby's admission to the NBU in Kijani and Tausi.

Figure 6.1 first 24 hours

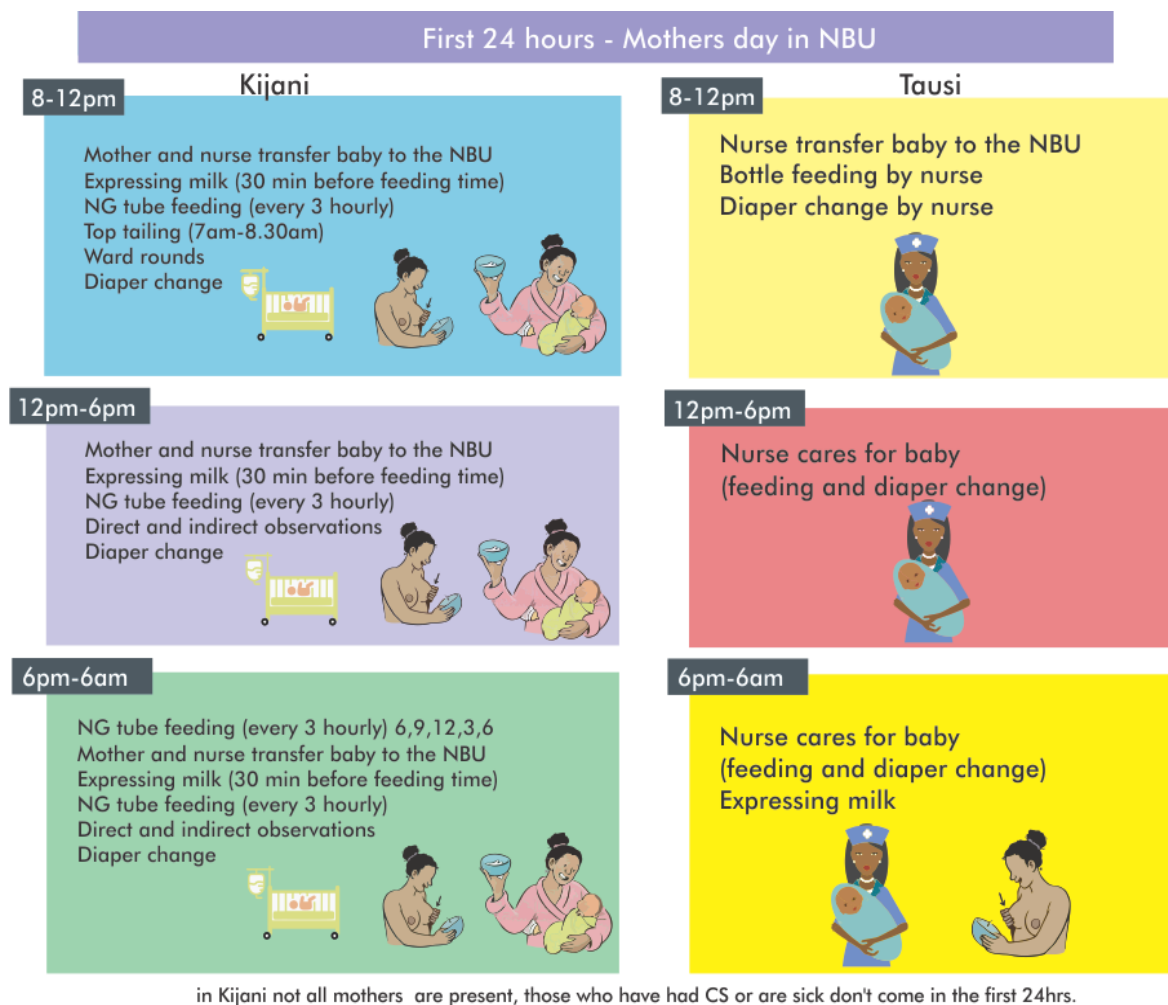


Figure 6. 1 Mothers' first 24 hours in the NBU

#### 6.4 After 24 hours of admission onto the NBU

Having provided a description of the mothers' involvement in care for their babies during the first 24 hours after admission, I will now discuss the experiences and involvement of these mothers in providing care for their babies in the subsequent days of their admission. It is important to keep in mind that a baby's trajectory was not always linear as their condition could swing from critical to stable and vice-versa depending on the reasons for admission. However, for ease of presentation, I start with a scenario where the baby was still in a critical

condition after the first 24 hours. I start by describing events in Kijani where the very sick babies continued to be cared for in room A while in the incubator and then proceed by discussing what happens in Tausi where such very sick babies continued to be cared for either in the NICU or in the premature unit 1 or 2.

#### 6.4.1 Involvement in care in the critical phase: Kijani's room A

At daybreak after the first night on the NBU -in this first night, mothers spent several hours in the NBU caring for their newborn-, for the mothers whose babies were critical but had been allowed to feed, the day's activities started with expressing milk and feeding the babies (see chapter 5). Mothers often struggled with expressing milk, either experiencing pain or struggled with producing the required amounts. Despite these challenges, minimal support and information on how to express milk or advice on the skills required for effective expression were provided. Whenever it was offered, this was either done by a nurse or by the nutrition interns (see chapter 5 on staffing), but this only happened when inadequate feeding was affecting the baby's weight gain or when a baby was observed to be dehydrated. While some of the interns just gave verbal directions to individual mothers, I observed one who practically expressed the milk for the mother.

Among all the nutrition interns, I noticed that this particular nutritionist intern was a bit different especially in how she offered support to the mothers. I later learnt through an informal conversation with her that she had also gone through the experience of premature delivery. She explained to me that she understood the difficulties experienced by these mothers, having been through it herself. She was more empathetic with the mothers. Whenever mothers complained about not having milk, this particular nutritionist intern would request to observe how the mother was expressing. This she did on an individual basis, offering one-to-one support to the concerned mother. As she stood by watching what the mother was doing, she offered instructions on what the mother needed to do. Not being able to express the required amount of milk often caused anguish for the mothers. It was frustrating for them seeing other mothers produce enough yet they struggled. At times there were some nurses and nutrition interns who would scold the mothers for not expressing enough and yet they didn't provide any suggestions on how to improve.

However, while help and support were rarely provided by the nurses or nutritionists, support and advice came from other mothers, as they encouraged each other as they expressed milk. Those struggling with expressing the required amounts would be advised by fellow mothers to avoid stress, help would be offered to those who did not know how to measure the milk



and the process of transferring it to the NG tube during feeding would be explained. In their interviews, mothers talked of expressing milk as the most difficult task to perform and at times talked of it as being very painful. Because of this challenge, the transition from NG tube feeding to breastfeeding was a source of joy for the mothers. They felt this was easier than expressing and were also clearly thrilled by holding their babies in their arms.

In Kijani, as described in box B, NG tube feeding was a central part of the caring activities that the mothers performed for their babies, from admission. Each day during the ward rounds the progress of the baby was reviewed by the clinical team and the mother was told verbally by the doctor or nurse how much milk she should feed her baby at each feed for the next 24 hours. If the NG tube was not already in place or if it had dislodged it was fixed by a nurse. After the initial fixing of the NG tube, the nurse or a nutrition intern would provide the mother with syringes for measuring the milk. *“Get a cup, express some milk, then measure with this syringe, connect this syringe to this tube and transfer the measured milk, when done remove the syringe and cover this pipe like this”* was the explanation that the mothers got from the nurse or the nutrition intern, with mothers rarely asking any questions. I observed some instances where no explanation about how to feed was offered after fixing of the tube. Such mothers would ask those sat next to them for help or they would turn to a nurse. In many instances the nurses would ask the mother to turn to their neighbours, referring to other mothers for help. In such instances, the peer support offered by the mothers who had been in the ward longer came into play. Those who’d been there longer, for over two weeks, moved from the novice to expert mothers. They gained some position and authority not just amongst fellow mothers, but also gained favour with nurses. I observed that it was somehow easier for these mothers to interact much more freely with the nurses.

Over the course of the observation period, there were days when, during NG tube feeding, a baby would choke and vomit which often caused panic with the concerned mother screaming for help from the nurses. Mothers had developed two main ways which they adopted to prevent this choking, one practical, and the other very much influenced by cultural beliefs. The practical trick some mothers used involved devising a way of controlling the flow of milk in the tube. They would pour some milk in the syringe and then pinch, fold and hold the pipe. I noticed many mothers were doing this and upon asking they told me they did this to regulate the flow of milk. If they felt the milk was flowing fast, they pinched the pipe, slowly releasing from time to time until they had finished feeding. I also noticed that many of the mothers would at times tear off a small piece of paper from the feeding chart and place

it on the baby's forehead. This they told me they did so as to prevent the baby from getting hiccups which they believed could lead to reflux and potentially choking.

In phase one of data collection (before the prolonged nurses' strike in public hospitals), after feeding, the mothers whose babies were on NG tube feeding also filled in the feeding charts and documented the feeding time. However, illiterate mothers struggled with filling these charts, with some leaving blanks despite having fed their baby. In phase two of data collection (after the nurses' strike), feeding charts were filled in exclusively by the doctor. As the doctors and the nurses were not always present feeding times, they relied on the verbal reports by the mothers about how much they had fed, there was no exact way of ascertaining the feeds given. At times some mothers would report about not having attained the required amount and would be encouraged to try and avoid stress in order to produce the required amount of milk. After filling in the quantity of feeds and timings, the mothers would receive a brief explanation regarding the days' feeding plan with direct instruction of the day's quantity of feed. For the majority of the babies on NG tube feeding in Kijani, feeding was scheduled every three hourly, (6:00 am, 9:00 am, 12:00 pm, 3:00 pm, 6:00 pm, 9:00 pm, 12:00 am, 3:00 am). Those breastfeeding did so regularly depending on need. Just as they care for normal babies, mothers would breastfeed whenever they thought a baby was hungry or when a baby was crying (See figure 6.2)

Once the babies had been fed the mothers started on the next task of the day, top-tailing. In general, all of the mothers undertook this task at the same time due to the once-daily availability of hot water, provided routinely at around 6.30 am each morning (see chapter 5). For those mothers whose babies were still in critical condition after this 24 hrs, and could not yet feed, the top-tailing was their first task of the day. Learning to top tail as well as NG tube feeding was another example of how mothers learned from each other. Top tailing took place with the babies inside the incubators. Standing side by side or in turns, mothers whose babies shared an incubator top-tailed their babies. As they top tailed, mothers next to each other conversed; some would voice their fears, to which other mothers would laugh and encourage them by telling them: *"the child is yours if you don't do it who will?"* In the discharge interviews, I asked the mothers how they learned how to top-tail. The majority of those interviewed reported that they just observed what their neighbours were doing and followed suit.

This informal peer support was also reinforced by the nurses, *"ask those next to you to show you how to do it"* mothers would often be told by nurses when they asked for help with something. As babies shared incubators and the incubators were arranged in a line next to

each other (see chapter 5), there was room for friendships and peer support to naturally develop among the mothers. Through learning these tasks from each other, relationships developed that set the ground for the emergence of supportive informal relationships and networks right from the very first days of admission (see chapter 7 on supportive relationships).

The NBU consists of different actors that include mothers, nurses, doctors, and other staff. These different actors play different roles within the NBU field and occupy different spaces as described in chapter 5. Looking at Kijani hospital's NBU, the context facilitated the emergence of a community of mothers, a place where ways of doing things exist, friendships and networks emerged which in turn supported peer learning and informal support systems.

After top tailing, the mothers would leave their babies and return to the postnatal ward to shower, take breakfast and do laundry before they came back to the NBU for the 9 am feeding time. When they came back at 9 am they would stay on until after the ward round which generally took place between 10:00 am and 1:00 pm. As described in the previous chapter, mothers in Kijani were expected to be present on the ward during the ward rounds. At the ward rounds, each mother would be asked by the doctor or clinical officer how the baby was, whether the baby was feeding well, passing urine and stool. The mother would then be told about any prescribed tests or investigations, but this also depended on which clinician was attending to the baby. From my observations, the interaction between the staff and the mothers was somewhat one-sided, where mothers never really actively engaged with the staff in terms of expressing their views on the treatment plan and tests. Once the decision on the treatment had been made, the mothers would be told what had been decided and instructed on what they needed to do. Although in their discharge interviews, mothers reported that they interacted well with the staff and were provided with the opportunity to ask questions, observation data revealed that not all the mothers did so. In the course of the observations, I came across two mothers whose babies were on oxygen therapy for over a week. Amongst themselves, these mothers would complain and question whether the oxygen was really necessary but would never really voice their views with the doctors.

After the daily ward round had been completed the mothers spent the hours that followed keeping to the prescribed three hourly feeding times. In between the feeds, many of the mothers would stay in the NBU sitting by their babies' incubators observing their babies and changing their diapers as required. In the interviews, it emerged that they felt this was necessary because there were many babies in the unit and very few nurses, they, therefore, felt the need to always be present. In a sense, they felt that care for the newborns had to be

a cooperation between them and the nurses. They were concerned that that the nurses were overwhelmed and understood that they needed to concentrate on the very sick babies, so they took it upon themselves to observe the babies' incubators to alert the nurses in case they noticed something wrong with their babies. For some of the mothers, it was important that they actively got involved in the care of their newborns. They explained that active involvement was also a way of showing the nurses that they were indeed concerned about their babies and were actively taking on the good mothering roles.

As part of the observations, they kept an eye on the needle and IV lines, checking that they were in place and that the IV fluid was flowing well. In case they noted a swelling or that the fluid had run out or was not flowing, they informed a nurse. Mothers were also very keen to ensure that the eye protection cover for babies on phototherapy was in place. The nurses would tell them to always ensure that the baby's eyes were covered while on phototherapy. After feeding their babies, they would cover the babies' eyes, place the baby back in the incubator, and turn on the phototherapy machine, as explained by one of the mothers:

*“Whenever they would fix those injections, I would keep an eye on him because when they were put he used to eat the pipe and the injection would come out/bend then the hand would swell. Then it had to be removed again so I would just observe him and then he also used to remove the cloth for the eye, yes so I would, I just wanted to be close to him, when he removes the cloth I put it back” (Kijani\_DI\_010).*

Those whose babies were on oxygen therapy were also very keen to ensure that the oxygen prongs and masks were properly in place. As they did this, they would also routinely change the position of the baby in the incubator. Some initially were scared of touching the oxygen mask or prongs. One such mother was Regina, who I noted would then turn to the mothers next to her for help as illustrated by the field notes excerpt below.

Regina had been absent from the ward for the better part of the morning and the doctors kept on asking where she was during the ward rounds. She came back to the NBU at around lunchtime. The oxygen mask on her baby's face had come out, she told the other mothers that her baby had removed the oxygen mask. When the other mothers told her to place it back into position, she declined and told them that she was scared of touching it. She walked away and requested one of the mothers to help her by placing it back on. The other mothers laughed and encouraged her to just place it back. Eventually one of the mothers volunteered to place it back on for her. *[Field notes Kijani Hospital]*

Giving oral medication as prescribed was also part of the daily caring activities undertaken by mothers in Kijani hospital's room A. They were instructed by the doctor or nurse on the quantity to give the baby. Some of the mothers who were NG tube feeding initially received unclear or conflicting information about how to give the medication from the MO interns. Medication for such babies was to be given via the NG tube, however, some mothers would receive unclear information and gave the medication orally. This resulted in a few instances where the baby choked causing such trauma and panic for the mother.

While many of the mothers spent most of their days in the NBU alongside their babies, sometimes a mother would return to the post-natal ward to rest. When this happened, mothers would remind each other about feeding times and the community spirit between mothers of helping each other was further manifested by the manner in which they would alert each other whenever a baby was crying and the mother wasn't present. "*Call so and so*", those going back down to the postnatal ward would be requested. Those who had exchanged their phone numbers with fellow mothers would be alerted via a phone call from their peers and asked to come up to the NBU.

For the mothers whose babies remained in room A, the routine for the subsequent days followed this similar pattern, catching a few hours of sleep either in the postnatal ward during the day or in between caring for their babies in the NBU. At night they would sleep in the postnatal ward or on the chairs or floor of the NBU. They stepped out for their lunch which was served in the postnatal ward at 1 pm and dinner which was served at around 4 pm.

As time went by, the mothers who had stayed longer in room A became a source of information and support for the new mothers, voluntarily offering help and advice to the new struggling mothers. At times I observed the nurses requesting such experienced mothers to offer help to the new ones. While this was appreciated by most mothers, there were a few who appeared to dislike being told what to do with regards to their baby. Such mothers were labelled "tough headed, know it all". "*All these babies are ours, therefore, we must show concern*", the "difficult" mothers would be told. I observed that the mothers who were labelled as "difficult" kept to themselves and rarely joined in the conversations with the rest. They were like the "outsiders" in the NBU community and other mothers would once in a while gossip about them.

In Kijani hospital, there was a strong communal sense among the mothers. Apart from educating each other, I also observed that mothers helped each other, for example in changing the position of a baby in an incubator in case the mother was not within room A

and the baby was lying uncomfortably in the incubator, others would lend each other mobile phones to communicate with relatives at home. Some mothers would refuse to express milk as required. Showing an effort and trying to express, albeit in vain, was more appreciated by both the staff and other mothers as opposed to not trying at all. Mothers who would just refuse or put in the minimal effort would be scolded for not taking good care of their babies. While the majority would not react to such alterations, some would insist on being left alone, *“this baby is mine, not yours”* they would tell the other mothers in the ward.

Offering each other emotional support formed a key component of the mother's daily lives in the NBU, they encouraged each other during tough sad times. The excerpt below from my field notes illustrates one such incidence where I observed mothers supporting each other emotionally.

Box D

**When things take a negative turn**

Atieno was informed this morning after weighing that her baby's weight had reduced. On receiving this news, she looked distraught throughout the morning barely uttering a word. Towards the 12pm feeding, she started expressing milk but soon stops and breaks down. This catches the attention of the other mothers who were sat next to her. Belinda asks her what the matter was and Atieno responds by telling her that she has been trying yet her baby lost weight. On hearing this, Belinda tries to encourage Atieno by telling her that she also gave birth to a very tiny baby but with time the baby had improved. *“If you get stressed up and start crying you won't be able to take care of your baby you will even loose milk, just take heart all will be well”*, She tells Atieno. One other mother points to her baby and shares that she also gave birth to a very premature baby adds *“you have to be strong for your baby don't give up”* (Field notes Kijani)

#### **6.4.2 NICU and premature unit of Tausi hospital**

By contrast with Kijani, in Tausi, while the babies were in the NICU or the premature unit, I observed that most of the tasks undertaken in caring for the newborns (including NG tube feeding, top tailing and diaper change) were undertaken by the nurses. There was a hospital policy that stipulated that such very sick babies were cared for by the nurses and as such the

staff to baby ratios (described in chapter 5) were much higher than in Kijani facilitating the implementation of the policy and excluding mothers from the hour to hour caring for their babies. As in Kijani, the very sick babies in Tausi were NG tube fed and this was only ever done by the nurses. One morning, as one of the nurses was feeding a premature baby, I asked him why they never let the mothers help with this task, he smiled and told me *“this is a very delicate procedure, there are steps to be followed before feeding, you have to check whether the previous feed has been digested before feeding, it is, therefore, a very critical task, something might go wrong if we leave it to the mothers, therefore we prefer to do it ourselves”*, he explained.

Unlike the mothers in Kijani who became involved in feeding their babies early on in their hospital admission, in Tausi the mother’s role at this phase when the baby was still very sick was restricted to expressing milk which they then stored in labelled bottles in the fridge for later use. If they were still staying in the hospital themselves (admitted in the postnatal ward) they expressed the milk in the breastfeeding room or their rooms in the postnatal wards. Those who had been discharged expressed milk either at home or in the breastfeeding room. Mothers did not always have to be on the ward during the feeding times. As explained in chapter 5, mothers in Tausi with very sick or premature babies were often discharged leaving behind their babies in the hospital.

In Tausi, I observed that most of the mothers who were providing expressed milk had a breast pump, a tool that I never saw being used by any of the mothers in Kijani. Some of the Tausi mothers who had been discharged would sit together in the breastfeeding room with mothers of the stable babies who were either breastfeeding or also expressing milk. As they expressed, they got the opportunity to interact with each other, though there were always only two to five mothers in there at a time and they rarely sat together for more than two hours.

Despite the hospital’s attempts to exclude the mothers from taking part in providing care for their babies while they were in the NICU and premature units, for one mother, involvement in care right from the early stage was important. During my observations, it became clear that she was very keen on being involved in caring for her premature son. Unlike the other mothers, she was always present in the premature unit when her son was being bathed. One morning she asked the nurse to let her change the diapers and to even oil her baby. Once she realised this was actually possible, she carried on doing it during her baby’s stay in the premature unit. However, she was always in the presence of the nurses when she was carrying out these activities. Once the nurses had observed her keenness in getting involved,

after bathing the baby they would then let her oil the baby and change the diaper. Every three hourly she would also come back in to observe the feeding process and carry out a diaper change. In her final discharge interview, she described how she had really wanted to be involved in the care of her son. She reported having observed and learned the characters of the nurses and was subsequently able to identify those most approachable and sympathetic to her situation, she was then able to negotiate her approach into being involved in the care of her baby in the premature unit.

*“The good thing is a few nurses do let you take part in so much you know. Like there those who when they were on duty you know they are comfortable with you doing the changing of the diaper, and telling you the baby the baby is like this [tell you a lot more about the baby], can I turn them if they have slept on one side for so long and they would be free and there are those who I think they like being in control of the entire situation”*

The majority of the mothers whose babies were in NICU and premature units were rarely present during the top tailing, they would come in towards visiting hours at noon to express milk and also to bring milk that they might have expressed at home. When they came in, I observed that they spoke with the nurses; after greetings, they would ask how their babies were doing and had good interactions with them. In the NICU there was one radiant warmer and one incubator and at any given time there could only be one and very rarely two mothers in the NICU. The two premature units each had one incubator, therefore, mothers of premature babies could be alone in the premature room. When left alone some would pray, sing, and gently caresses their babies in the incubator. When accompanied by their husbands, I observed that at times the nurse would excuse herself for a couple of minutes, giving them time to be with their baby. Changing the diapers for the babies in the NICU was only done by the nurses. As the nurses spent a considerable amount of time in the NICU and premature units, they continuously checked on these babies. All of the observations and giving of medications was the sole preserve of the nurses.

In the discharge interviews, a recurrent issue expressed by the mothers who had been discharged leaving behind their baby under the care of the nurses was the issue of separation (further discussed in chapter 7). They appeared to feel powerless in the wards as indicated by one of the mothers’ statement during an informal conversation with me,

*“I tend to come in only during visiting hours just to bring milk because even if I stay here, there is nothing much I can do anyway”.*



Since most of the caring activities were treated as nursing roles, they left the baby under the care of the nurses. It appeared that these mothers were very careful also not to appear to interfere with the nurses under whose care their babies remained when they went home.

## **6.5 Involvement of mothers in the care of the stable newborns**

As described in chapter 5, when babies condition improved and stabilised, they were transferred to different rooms in both study hospitals; Room B and KMC for Kijani hospital and to the general NBU ward for Tausi hospital.

### **6.5.1 Kijani's room B and KMC room.**

Once babies improved and became stable in Kijani hospital, they were transferred to either room B or KMC if they had been born prematurely. In Kijani hospital, when a baby was moved from room A into room B, or straight to the KMC room, the mothers continued with the daily caring activities that they had been undertaking while their babies were in room A. They carried on with daily top-tailing, feeding, changing diapers, giving oral medication and observations (keeping a close eye on the baby). Having already been performing these tasks for several days, when it was time to move on to room B or KMC, the mothers appeared to be at ease and comfortable with caring for their babies; by now they had become experts in the task. Even though their babies had been moved from the incubators of room A to the cots of room B, the activities carried out by the mothers in room B of Kijani hospital were more or less a continuation of those they had been undertaking in room A.

The mothers whose babies were moved into room B also still had their sleeping space in the postnatal ward on the first floor (see chapter 5). By virtue of keeping their shared sleeping spaces and the fact that their babies were now sharing cots, the network and friendships among the mothers in room A continued in room B. The mothers whose babies were in room B had all met at one time or another in room A or in the post-natal ward where they shared a sleeping area. While caring for their babies, mothers would talk to each other and continued assisting each other. Some bonded more with others and would remind each other of feeding times, call each other to attend the baby if need be, serve food and keep it for each other if their friend was not in the postnatal ward when food was served, lent each other mobile phones to communicate with relatives at home and at times lent each other diapers.

In Kijani hospital, the premature babies who were well and only needed to gain weight were transferred to the KMC room. Some of whom were still on NG tube feeding were moved to KMC mainly due to lack of space as a result of increased new admissions of very sick babies.

For mothers of such babies therefore, the task of expressing and feeding via NG tube continued alongside the other tasks of top tailing, changing diapers and giving oral medication. Mothers whose babies were taking oral medication would follow up with the nurses to ensure that this was administered. If this was not done, they carried their babies back to the NBU to get the medication. This was necessitated by the fact the nurses spent most of the time in the main NBU, so if KMC mothers needed their help they had to walk back with their babies to the NBU where the nurses and clinicians were.

With time the babies who had been transferred to either B or KMC while still feeding through the NG tube were slowly transitioned into cup feeding and finally were allowed to breastfeed by the time of discharge. This transition from NG to cup feeding was a challenge for some of the mothers. They had concerns especially if the weight of the babies stagnated or declined during their stay in KMC or room B. Informal conversations with such mothers revealed that they felt that with cup feeding, some of the milk spilled and therefore they were concerned about the baby not getting the required amount of milk. For them, feeding also took longer as at times the baby would fall asleep while feeding. This impacted on the mothers' stress and emotional wellbeing, despite the baby being in a stable state. These experiences and transitions will be discussed further in the next chapter.

While most of the mothers were happy with the progress of their baby in room B and KMC, I observed scenarios where some of the mothers requested that their baby be put back on NG tube feeding because with the tube they were certain that the baby was taking in the required amount of milk. When this happened, either the nutritionist or the nurse would explain to them that the baby was well and as discharge was nearing there was the need to ensure that the baby could slowly move from NG tube feeding to cup and finally to breastfeeding, "*you will not be NG tube feeding at home, so just try your best*", the mothers would be encouraged.

In the KMC room, mothers were introduced to a new task of providing Kangaroo mother care to their babies. On arriving in the KMC room, the accompanying nurse would show a mother to her bed. The nurse would then show her how to strap the baby in the kangaroo position. The nurse in charge of the NBU was very passionate about KMC and each day she would pass by KMC to check on the mothers and the babies and give a health talk about KMC. This kind of health talk would only be given in the KMC room. She would tell the mothers about the benefit of KMC. Later in phase two of data collection, she added a component of infant massage to her health talks. She would demonstrate to the mothers how to massage their babies, occasionally joking with the mothers and encouraging them to put their babies on KMC. The first question she would ask those who were not doing KMC was

why this was the case, “*we have brought you here to do KMC not to sleep, the more you do KMC the faster you will go home, are you talking to your babies? How about massage? Have you done that today?*”, she would ask the mothers. Whenever mothers saw her walk into the KMC room they would smile. Once in a while, the nurse in charge would request one of the champion mothers (see chapter 5) to come in and talk to the mothers in KMC about their experiences with KMC and its benefits.

KMC brought together mothers who had spent time together while their babies were in room A as well as some who might have previously moved from A to B. Here in KMC they spent all their time together, each mother now had their own bed for herself and her baby. The KMC room emerged as a favourite room for these mothers. Here, apart from just completely caring for their babies on their own, they often talked about how they now felt relaxed and in control of their babies. Being here meant no more having to walk up and down the stairs every three hours to feed and change diapers and to observe how their babies were doing as the case had previously been while their baby was in room A or room B. This is also an indicator of the transitions for the mothers, from a state of partial separation to a place where they were able to effectively bond much more with their babies outside the incubators in the NBU.

### **Box E A typical day on the NBU for mothers of stable babies**

**Kijani hospital:** After her 6:00am feed, Jane went back to the postnatal ward and returned to the NBU at about 7:30 in the morning, Jane walks in to find other mothers already busy changing diapers and top-tailing. She greets the other mothers, opens the incubator and looks at her daughter. Her daughter was born prematurely and is also on phototherapy. She starts by checking the diaper, then she walks to get a small basin of warm water to top-tail her daughter. Using the warm water and cotton wool she cleans her baby starting by wiping the face, head, and then the rest of the body. As she cleans the baby, she smiles, occasionally talking to the baby. She turns to me and says; *“I can see she is growing; she was so tiny at first”*. She then oils the baby and changes her into a clean diaper. It is now about 8:00 when she finishes the top-tailing process. She then excuses herself and tells me *“let me go back to down and shower then I come back”*. After about 30-40 minutes, she comes back looking fresh, having had a bath. She then pulls up a plastic chair next to her baby’s incubator and begins to express milk. She expresses by hand into a plastic cup, occasionally taking breaks and sighs lamenting about how hard it is. She tells me that it is a very tiring thing to do. She however does not give up until she manages to express enough milk which she measures in a syringe. She is now giving 20 mls. Having expressed enough, she stands up, opens the incubator, removes the stopper from the NG tube and transfers the milk from the syringe into the NG tube. It is now about 9:40am when she is done with the feeding. She proceeds to wash the cup and the syringe in the cup washing room and then returns to sit by her baby’s incubator as she waits for the ward round. When the doctors get to her baby, the medical officer greets her and asks her how they were doing. She had reported in the last round that she was struggling with getting enough milk and had been advised to eat well and to try and avoid stress. Both her and the doctor are happy that she is now able to get enough milk. Once the doctors finish with their review of the baby, she is informed to continue giving 20mls every three hourly. It is past 11:00am when the doctors finish reviewing her baby. She then begins expressing milk for the noon feeding. After feeding and cleaning the cups, she hangs around the ward seated by her baby’s incubator and chatting with the other mothers. Occasionally she stands up to adjust her baby’s position and change the diapers. Towards 2:00pm, she requests one of the mothers who is present to call her in case her baby cries. She excuses herself and goes down to the maternity/postnatal ward for her lunch and returns at 3pm for the 3 pm feed. She continues with the three hourly feed and only leaves to go have her meals and catch a few hours of sleep.

### 6.5.2 General NBU ward in Tausi

For nearly all of the mothers who gave birth in Tausi and whose babies were admitted to the NBU, it was only when their babies were moved to the general ward of Tausi hospital's NBU that their journey into active involvement in caring for their babies began. Babies admitted with jaundice or infection were generally the ones admitted into the general ward after the two hours observations in the observation area by the nurse, very sick babies from the NICU and premature babies took longer to be transferred to the general ward (see chapter 5). Prior to this move, the majority of the mothers were only involved in expressing milk and it was in the general ward that mothers were progressively introduced to other tasks such as top tailing and diaper change.

Stable babies were cared for in the general ward (see chapter 5). For the first few days following admission to the general ward or transfer to the general ward from the NICU or premature unit, the nurses would top tail the baby as the mothers stood nearby observing what the nurse was doing. For the stable babies who did not require intensive care but whose mothers were still admitted to the hospital, it was easier for the nurse to make a phone call to the mothers in the morning when their babies were awake. Well mothers who had delivered in Tausi hospital were admitted in the hospital for 3-4 days in the postnatal wards.

During this time when the mothers were still admitted in the postnatal ward, as the nurses prepared the warm water and washed the basins for bathing, the mothers would take that time to breastfeed their babies in the breastfeeding room. One by one, the mothers would be called upon from the breastfeeding room to bring their babies for bathing. During these initial days, while the baby was in the general NBU ward, as the nurse bathed the baby, the mother would be standing next to the nurse keenly watching what the nurse was doing. There were nurses who took this time to teach the mother the steps of bathing a baby, especially for first-time mothers. Information provided included the need to set everything ready before undressing the baby, ensuring that the room was warm, how to check on the temperature of the water using the elbow and the process to follow. The process taught to the mothers was to begin by first wiping the eyes and face. After the face, the nurse would then place the baby in the basin and wash the head first followed by the rest of the body. This teaching moment took some minutes, so those who had delivered via caesarian (CS) would be given the opportunity of sitting on a chair next to the nurse.

Once the bathing was done, the baby would be placed on a radiant warmer, covered by linen in order to keep them warm and dried, oiled and then using pieces of cotton wool the mother

would be taught about how to care for the cord. *“Divide the cotton wool into 4-5 pieces, wipe one side first, one stroke on each side always using a different piece to avoid infection”*. The nurse would then put the diaper on for the baby and dress the baby in the hospital gown, change the linen on the cot or incubator and then allow the mother to go ahead and breastfeed the baby again in the breastfeeding room as she cleared the surface, and prepare the space for bathing of the next baby.

After a few days (2-3 days post-delivery) of the nurse bathing the baby as the mother observed, the mother would then be allowed to bathe the baby herself. *“You have seen how I have been doing it, today you will do it and I will observe you do it”*. Mothers would then bathe babies as the nurse observed, this provided the opportunity for them to ask questions. After this, on the subsequent days, the nurse would only prepare the bathing water and ask the mother if she was okay to now do it on her own; most of them then carried on bathing the baby by themselves. A number of the mothers would be present during the morning bathing hours including some of those who had opted for early discharge from maternity. Those babies whose mothers were absent would continue to be bathed by the nurses.

I observed that just like in Kijani, initially, mothers struggled with expressing milk. This was often not taught to the mothers. Mothers felt that it was not only tiring but at times painful. These struggles with expressing milk and breastfeeding were also voiced by the mothers in the interviews conducted at discharge, they reported not knowing how to position the baby. In the breastfeeding room, some of the other mothers would offer to help those that were struggling, instructing them on how to hold the baby and show others how to use the breast pump. For those who had opted for early discharge, when they were not around, the nurses would bottle feed the babies either with their expressed milk but if there was no breast milk available, the babies would be given formula milk. Nurses would also change the diapers of the babies whose mothers were not around. Feeding in the general ward was mostly on need when the babies woke up, mothers still admitted in the postnatal ward would be phoned by a nurse to come to the unit. All the phone numbers of the mothers were kept on a file that was placed in the nurses' station. Even for those in hospital, there were times when they could not be reached so the nurses went ahead to feed their babies using the breast milk if they had expressed or fed the baby formula milk.

The mothers with babies in the general NBU ward also had the task of washing their breast pumps and feeding bottles that they used in storing the expressed breast milk. In the general ward, there were also babies on phototherapy, therefore the mothers would after feeding or changing their babies' diapers, place the eye protection cover for their babies and then put

them back on the cot or incubator for phototherapy. Mothers in Tausi's general ward were also keen checking for any changes in their babies and would bring up issues of concern to them with the nurses or the doctor. They would keenly look at their babies whenever they were changing diapers or breastfeeding. Unlike Kijani, mothers were generally not required to be around during ward rounds. As these babies were being treated by different doctors, the timing of the review by the doctor/ward round was not standard. Most of the time the doctors would come in the absence of the mother, the mothers would then inquire from the nurses regarding the doctors' review. If they need to talk to the doctor, they requested to be phoned/alerted when the doctor came in. As mothers in Tausi were not present continuously on the NBU as the case was in Kijani hospital, their routines varied.

### **Box F A typical day on the NBU for mothers of stable babies**

#### **Tausi Hospital:**

At around 8:00am, the nurse on duty phones Anna who is still asleep in her room to come to the NBU, *“the baby is crying”* the nurse tells her. She walks in about 10 minutes later. Having gone through a C-section she is clearly still in pain from the surgery, she walks in slowly looking very tired. She walks to the general ward to her baby’s cot. After a diaper change, she carries the baby to the breast-feeding room for feeding. As the nurse is busy top-tailing another baby whose mother is not present, she sits in the breast-feeding room with her baby, waiting to be called by the nurse. The nurse alerts her when she is ready and shows her how to top-tail. During the bathing she is offered a chair by the nurse to sit down as she observes an offer which she declines. After the bathing she takes the baby to the breast-feeding room to feed again. When the baby is asleep she goes back to her room. This routine of coming to the newborn unit when the baby is awake or every three hours to feed and change the diaper when needed is her routine the whole day. During her exit interview, she tells me this about how days were, *Uhh a day never starts or never ends, so I would say that we are up or we are awake on and off on and off throughout. I can’t really wait to start at this time... yeah, because mmh maybe I can begin at one at night because that is when the baby wakes up.... I don’t know now if that is the beginning or the end of the day.* Anna’s description about her day sums up what it is like to have a hospitalized sick newborn It involves feeding, top- tailing and frequent movement in and out of the newborn unit.

The descriptions of the context and involvement of the mothers in providing care for their babies in the two hospitals in the days following the first 24 hours of admission suggest that the mothers in each hospital faced very different experiences. The mothers in Kijani were significantly involved in providing routine care for their babies even when they were in a critical phase whereas the mothers in Tausi only became involved in practical caring once their babies had moved to the general ward and had been shown by the nurse how to carry out the tasks such as diaper changing and top tailing.



An outline of the tasks that the mothers were involved during the second and subsequent days after admission in each hospital is shown in figure 6.2.

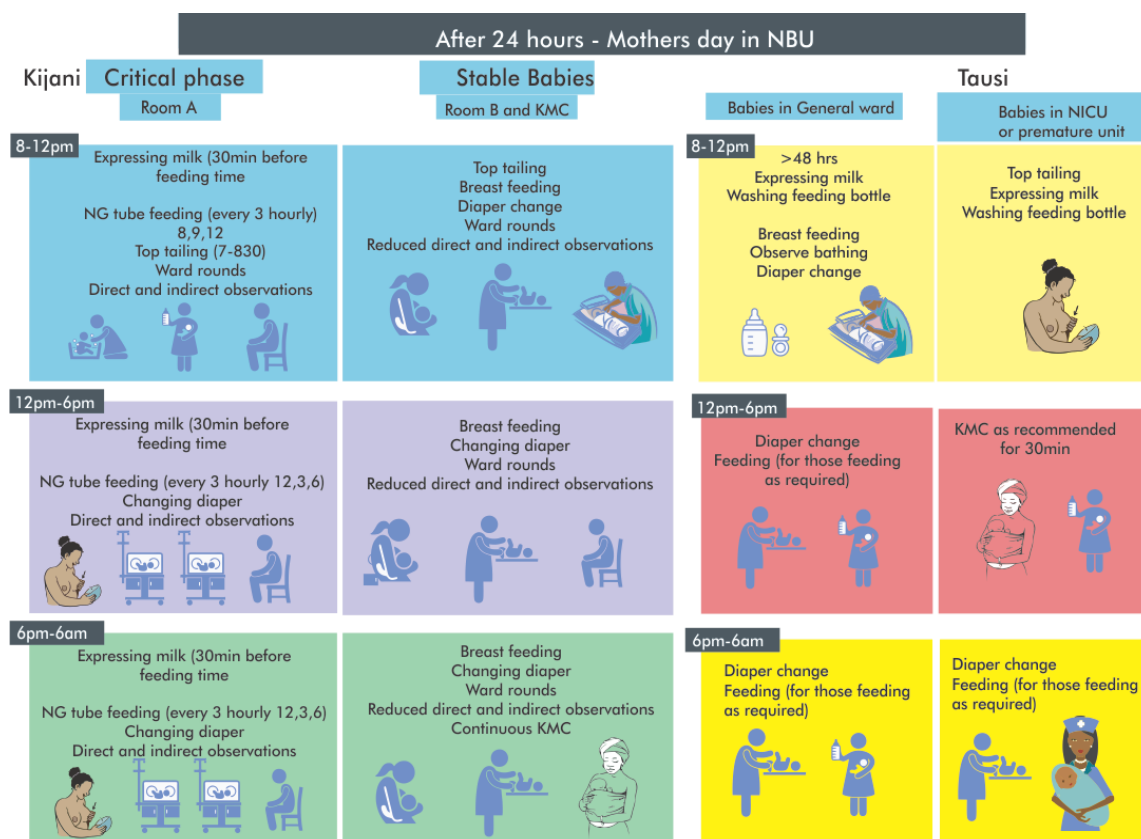


Figure 6. 2 After 24 hours

## 6.6 Summary

In summary, the mothers in Kijani were expected to become involved in caring for their sick babies immediately on admission with minimal preparation and little support from the nurses (see table 6.2). However, this was rarely a source of complaint, most of the mothers appeared glad to comply taking on the charge of the bedside care with only occasional demonstrations of fear and confusion once the first 24 hours were past and while their babies were improving. To them, their active involvement in caring for their babies was important both for their own sense of being able to bond with their baby and start taking on the role of a mother and as part of showing the nurses that they were interested in the wellbeing and progress of their sick babies. Mothers in Kijani were also sympathetic to the nurses' workload, therefore, they felt it was necessary for them to take on the bedside care of their babies. Some mothers struggled more than others in coping with their very tiny babies and were more reluctant to take on tasks, perhaps for fear of hurting their baby. Other mothers would provide support.

The mothers in Kijani stayed in the hospital the entire duration of their baby's admission, their babies shared incubators and these mothers also shared beds in the postnatal ward. As they spent so much time together, friendships developed that supported the emergence of informal peer support networks within the mothers' community. They supported each other emotionally, with material things and those struggling with tasks such as changing diapers received support from fellow mothers on the NBU. Within this emergent mothers' community observed in Kijani, the mothers had their own space; spaces that the nurses and clinicians rarely entered. While they had their own spaces and developed their own supportive community, they had to conform to the rules and expectations imposed by the nurses in order to fit not only in the NBU but also into the mothers' community. Mothers had to conform to the rules and expectations in order to fit not only in the NBU but also into the mothers' community. For example, each mother was expected to comply with feeding times, express milk and feed the baby as prescribed. Those who complied with these expectations were considered good mothers and earned a place in the mothers' community while those who did not follow the rules or failed to meet these expectations were considered bad mothers and thus "outcasts".

By contrast, the mothers in Tausi spent minimal time together and had much fewer opportunities to develop friendships and networks with their fellow mothers. The context in Tausi hospital was different, with individual sleeping spaces and options for early discharge, for these mothers. The only space within which they could interact with one another was the breastfeeding room. Tasks such as feeding and diaper change were also initially undertaken by nurses; unlike in Kijani where the communal undertaking of these tasks allowed the mothers to share experiences. The social and economic capital of the Tausi mothers allowed them access to individualized treatment from the nurses but hampered their ability to develop informal support networks with the other mothers. Kijani mothers drew more support from the strong informal peer support networks as opposed to the Tausi mothers who drew more support with the tasks from the nurses.

The mothers in Tausi also only started taking on tasks such as feeding and bathing days after their baby's admission. The first 24 hrs saw the care of the baby being completely under the nurses as the mother recuperated. This was followed by initial one-on-one learning sessions where mothers were progressively introduced to and taught how to perform tasks such as bathing by the nurses before eventually performing these tasks on their own. Some of the mothers in Tausi also faced the same worries with the tasks that mothers in Kijani had, they worried about the size of the baby.

Table 6. 2 Summary of mother's daily activities

		<b>Comparison</b>		
<b>PHASE</b>	<b>TASKS</b>	<b>Kijani</b>	<b>Tausi</b>	<b>Source of support</b>
<b>Critical Phase</b>	<i>Feeding Top tailing/ Bathing Diaper change Observations</i>	Caring tasks are taken on by the mother within 24 hours of admission.	Task taken on >24 hours after admission.	In Kijani, mothers mainly learn from each other with minimal support from the nurses. In Tausi, there was no learning from each other. Support with tasks provided by nurses In Kijani Mothers observe each other's babies in Kijani. No observation of each other's babies in Tausi. Peer learning, social and emotional support evident among the mothers in Kijani. No peer learning, social and emotional support within the first 24 hours in Tausi.
		Mothers NG tube feed	Babies NG tube fed or bottle-fed by a nurse	
		Babies are top tailed by the mother	Babies bathed by a nurse	
		Mothers present throughout in the NBU and directly observe their babies. (Alerting nurses, fixing oxygen masks out of place, turning babies, fixing eye protection during phototherapy).	Mothers absent from the NBU and therefore no direct observation of their own baby.	
<b>Stable phase</b>	<i>Feeding Top tailing/ Bathing Diaper change Observations KMC Giving oral medication</i>	Mothers give oral medication	Mothers do not give oral medication	Peer learning, social and emotional support evident among the mothers in Kijani. In room B mothers observe each other's baby. Some extent of peer learning observed in the stable phase in Tausi in the breastfeeding room. In the general ward, mothers do not observe each other's baby.
		Mothers breastfeed and some continue to NG tube feed.	Mothers breastfeed	
		Mothers top tail	Mothers bathe their babies	
		Mothers place baby on phototherapy after breastfeeding.	Mothers place baby on phototherapy after breastfeeding.	
		Mothers change diapers	Mothers change diapers	
		Continuous KMC and mothers continue to observe their own baby in the KMC room	Intermittent KMC	

## 6.7 Discussion

In the previous chapter, I illustrated the structural, social and economic differences between the two study hospitals. I also highlighted the inequities in the social and economic capital of the women across the two study sites. In this chapter, I have shown how these inequities translate into the tasks the mothers undertake while their baby is in hospital and the support they receive to facilitate their involvement in care. Parental involvement in care has been highlighted in several studies from HIC settings as an important element of the implementation of FCC (De Bernardo, Svelto, Giordano, Sordino, & Riccitelli, 2017; R. Flacking et al., 2012; Staniszezwska et al., 2012; Westrup, 2015). These studies also note that involvement in care results in better parental experiences. However, babies born prematurely or those born sick require specialised care provided by skilled health care professionals and at times need care under advanced medical technology, as such, in HICs care in the NBU is highly medicalized (Herbst & Maree, 2006). While medical technologies and advances in clinical care have contributed to reducing neonatal mortality, they have also been found to interfere with parents' ability to participate in the care of their sick baby (Wigert et al., 2008)

Evidence from the HSD-N study (which studied neonatal care in Nairobi from 2014 to 2019), as well as stakeholder meetings that were held as part of this study (Murphy et al., 2016; G. A. V. Murphy et al., 2018), suggest that nurses working in NBUs in Nairobi (including nurses from the two study hospitals) perceived that by necessity NBU care should be highly medicalized. Providing care for a sick newborn was viewed as being highly specialised with tasks such as NG tube feeding being critical tasks that the formal norms of neonatal care stipulate should *only* be undertaken by nurses. That is, the formal norms of care in Nairobi NBUs are that tasks such as NG tube feeding should only be undertaken by nurses and for other tasks such as diaper changing and washing, initial training and support should be provided by nurses. However, the shortage of staff and lack of resources in Kijani meant that mothers performing these “nursing” tasks had become a practical norm. Additionally, the critical staff shortage impacted the nurses' ability to support and supervise mothers performing these tasks leaving them, initially at least, often alone and confused by what to do and how to do it.

By contrast, in Tausi there were sufficient nurses to undertake these tasks, so the mothers were relegated to the role of ‘observers’ until their babies came off NG tube feeding. From a biomedical perspective, the practical norms of care in Kijani had the potential to expose the babies to significant risk of harm (as evidenced by one mother's panic as their baby

choked) but from the mothers' perspectives, while they were initially fearful, they quickly learnt how to cope and many enjoyed the opportunity to be fully involved in the care of their baby. The mothers in Tausi received far greater biomedical support but were left with feelings of separation and helplessness for a much longer period during their baby's hospital stay (discussed further in the next chapter).

While the NBU in many high-income settings is highly medicalized, studies from HICs have reported that mothers do become involved in care while their babies are in hospital with supervision from the nurses just as was observed in Tausi. For instance, a national survey conducted in Europe in 2011 as well as a subsequent survey conducted in 2014, noted very high percentages of parents reporting being actively involved in the day-to-day care of their newborns. In both surveys, amongst the tasks that these parents reported having been involved in included feeding and diaper change. Additionally, both surveys noted that over 75% of parents reported high rates having received encouragement to have skin-to-skin contact with their baby (Burger, King, & Tallett, 2015; Howell & Graham, 2011). However, in the UK setting, which has a better nurse to baby ratios, mothers receive formal support with these tasks and learn from the nurses rather than each other.

The UK quality standards for neonatal care highlight the need for parental involvement in tasks and further emphasize the importance of offering support to the parents with breastfeeding and expression of milk (NICE, 2010). In the 2010 national survey by the Picker Institute in England, 76% of respondents reported having received breastfeeding support and 86% reported having been provided with equipment to support milk expression such as breast pumps respectively while their baby was in the hospital. This is in contrast to the observations made in this study where in both study hospitals, breastfeeding support emerged a key area where mothers experienced a deficiency in formal support. Further, neither of the two study hospitals provided equipment for the expression of milk. In Kijani hospital, mothers bought their own cups while in Tausi they purchased their own breast pumps.

While none of the mothers in either of the two hospitals were observed to receive any formal support for breastfeeding, as the results in this chapter have shown, the mothers in Tausi received formal support from the nurses in how to undertake the other caring tasks (e.g. washing the baby and diaper changing). The mothers in Kijani were largely left to fend for themselves and turned to their fellow mothers for the support they required; support that may have been socially helpful but not always 'correct' from a biomedical perspective.

The lack of resources found in Kijani meant that, through necessity, the mothers developed individual skills in caring for their babies and alliances with other mothers resulting in the formation of informal peer support networks. In the context of the NBU, these skills and alliances with other mothers facilitated the development of a form of cultural capital that helped them to survive in the challenging environment, developing a sense of control and self-efficacy in caring for their babies. That is, the involvement in care in Kijani enabled these mothers with low social and economic capital to gain cultural capital as ‘expert mothers’ in the field of the NBU. Mothers who had been on the ward longer gained a position (of status) and respect and they were heavily relied upon and encouraged by the nurses to assist with offering support for the newer mothers. That is, their gains in cultural capital increased the respect they received from those with professional authority in the NBU. The formation of these supportive alliances is a demonstration of resilience in the face of “structural violence”. This resilience, in turn, translates into better experiences, as we will see in the next chapter. By contrast, mothers who refused or were unwilling to ‘learn’ and adapt to the culture of the NBU were labeled as ‘bad mothers’ and became isolated from the other mothers and treated with less respect by the nurses.

These data suggest that in settings of high social and economic inequality, the practical norm of involvement in care is important not only in the process of facilitating mother-infant bonding which is beneficial for both mothers and baby (Fernandez Medina et al., 2018; Staniszewska et al., 2012) but also in helping mothers who have very little economic, and social capital when they are admitted to develop cultural capital and earn the respect of nurses in the context of the NBU. These practical norms further facilitate the development of important coping mechanisms for such mothers through the development of a mothers’ community and informal support networks which are discussed further in the subsequent chapter.

## **7. RESULTS 3: EXPERIENCES OF MOTHERS OF HOSPITALISED NEWBORNS: MOTHERING IN THE FACE OF UNCERTAINTY.**

### **7.1 Introduction**

In this chapter, I draw on the narratives of a sample/subset of the mothers observed whose babies were admitted immediately after birth onto the NBU of the two hospitals to describe their experiences at this challenging time. In this chapter, I now describe how the mothers themselves talk about what happened during the hospitalisation and immediately following the discharge of their baby. I also describe the coping mechanisms they employed in both hospitals, taking into consideration the differences and their vulnerabilities. The data presented in this chapter comes primarily from the narrative interviews conducted with 12 women, six from each hospital, that were conducted 2-6 weeks post-discharge in their homes.

To build a coherent story and holistically capture the stories of these women, this chapter is structured around the ways in which the women talked about their experiences during the narrative interviews. These data are presented as six main themes as follows:

- 7.2 Description of the mothers: In this section, I briefly provide a description of these mothers and where they live.
- 7.3 Life in the NBU: In this section, I discuss the lived experiences and varied emotional trajectories of the 12 mothers across the two NBUs. This section is divided into 5 subsections:
  - 7.3.1 *Shock and confusion*. Here, I highlight the emotional experiences that characterise the birth and entry into the NBU.
  - 7.3.2 *Doubts and Frustrations*. This section describes the daily emotional struggles and frustrations of these mothers.
  - 7.3.3 *Relationships*. Here I describe the tensions experienced by the mothers as they tried to become good mothers.
  - 7.3.4 *Fears and anxiety*. In this section, I discuss the fears experienced by the mothers. This section is structured around the broad theme of “uncertainty”, identified in the analysis as central to their experiences.
  - 7.3.5 *Anticipation Happiness and excitement*. Here I highlight the changes in emotions that come with the improvement of the baby’s condition.
- 7.4 Coping strategies: In this section, I talk about how the mothers navigated their fears and anxieties while in the NBU.

- 7.5 Getting home: In this section, I report on their fears and coping strategies and some of the tensions that they experience following discharge.
- 7.6 Discussion and conclusion: In this final section I compare the results from this study with those reported from other studies. Additionally, I highlight what has been done in other settings to help mothers of hospitalised sick newborns cope better.

## **7.2 Description of the mothers**

For the narrative interviews, I interviewed a total of twelve women, 6 from each study hospital. As highlighted in the previous two chapters, mothers from the two study hospitals came from quite distinct social backgrounds and this was further manifested by the type of homes and the neighbourhoods they resided in. The six women from Tausi hospital lived in less noisy middle- income neighbourhoods. While a majority lived in secluded rented permanent residential flats, some lived in bungalows with their families. Two of the Tausi women were unmarried and had moved back to their parent's homes post-discharge to seek support from their families with the care of their newborns. The other four lived in their marital homes and had employed home helps who assisted them with the house chores and with the care of the newborns.

The six women from Kijani lived in informal settlements, in one room iron sheet houses. In contrast to the homes of the women from Tausi, these one-roomed houses were accessible via narrow cramped corridors. The environment was often noisy and crowded with activities, human traffic and loud music from their neighbouring houses. Neighbours interacted with each other as they walked past or went on with their daily house chores such as washing clothes and cleaning. Surrounding these houses were very many small scale vendors selling foodstuffs. The Kijani women were mostly home alone when we visited. In tables 7.1 and 7.2, I describe some of the mothers from the two study hospitals. In table 7.3, I provide a summary of all the mothers who took part in the narrative interviews.



Table 7. 1 Description of two of the mothers from Kijani Hospital

**Lucy** is a 41-year-old fourth-time mother. She lives in a one-roomed semi-permanent house in a neighbouring slum with her husband and three children. She has no formal education and is a homemaker. She went into labour at night when her husband had gone to work. She rushed to the nearest facility where she was referred to Kijani. Her husband had gone to work that night. She then took a motorcycle taxi to get to Kijani by herself, it took her about 40 minutes to get to Kijani. She had a supportive husband who not only provided money for the transport to get to the Kijani but also helped with looking after her other children at home in her absence. Her husband also visited her in the hospital.

**Peninah** is a 27-year-old mother. She has dropped out of school in high school and runs a small scale business near her house. She lives about 20 kms from Kijani hospital with her husband in a two-roomed house. She has a sister who also resides close by. This is her second pregnancy. Just like in her first pregnancy, she started her ANC visits in the third trimester. She had been advised to go for a scan. She explained that the nurse had told her that she could not feel the baby on palpation. She mentioned that she was scared of going for the scan and thus never went for it. She went into labour prematurely one night. Her husband sought help from one of the neighbours who recommended going to Kijani. This neighbour is a taxi driver and he agreed to drive them to the hospital. She gave birth to twins. Her babies were both in the incubator for two weeks before being moved to the KMC room for about a week. Her husband would visit mostly in the weekends as he had to go work. Her sister took over the running of her business during the time she was admitted.

Table 7. 2 Description of two of the mothers from Tausi Hospital

**Brenda** is a 36-year-old third-time mother. She lives in an upmarket flat about 5kms from Tausi hospital. She has a college degree and works as a professional music teacher. This was her third, but the most difficult pregnancy. She delivered through a caesarean section. Talking about her pregnancy, she thinks that her baby was post-dated and attributes the main reason for the admission to have been because her baby had ingested a lot of secretions at birth. Her husband and a cousin who is a doctor were present during the delivery. She explains that the baby was then moved to the nursery as she remained for about one and a half hours in the theatre and then was taken to her room to recover. Despite her early discharge from the maternity ward, she opted to stay in the hospital until her baby was discharged. Her two previous deliveries had been at a more expensive private hospital. In the first week of discharge, her mother-in-law was there to give her support with caring for the baby and she also appreciated having a very supportive house help whom she said had lived with her for the past ten years. She, therefore, said she didn't have to strain so much post-discharge.

**Maria** is a 25 years old first-time mother with a college certificate. She lives in a rented middle-income neighbourhood that is about 18 kms from Tausi hospital. She is self-employed and runs the family business. She had a smooth pregnancy apart from the first two weeks where she says she felt nauseated. Having gone past her due date, delivery via caesarean section was recommended. However, the surgery never happened, she managed to push and deliver while inside the theatre. She explains that she was scared of going through surgery, such that when she saw the doctor walk into theatre she gathered the strength and courage to push and deliver normally. Her baby did not cry at delivery and she said that the explanation offered to her was that the baby was being taken to the nursery because he had ingested a lot of secretions. Her baby's condition deteriorated on the third day and since there was no space in the ICU, the doctor informed her that he was contemplating a transfer to a separate private facility. This worried her because she wasn't sure her insurance cover could cover the bill. Her baby improved and was not referred outside, though he stayed in the hospital for close to five weeks. She opted for voluntary discharge and would visit the baby on a daily basis. The commute was hard due to the traffic and because at times she had to connect twice through central town. During her stay in hospital, the family business was now being run by her brother. Post-discharge, the baby still had a wheeze and due to his fragility, she informed us that she had opted to stay at home and look after her son till he was six months old.

Table 7. 1 Description of the mothers who took part in the narrative interviews.

Participant ID	Place of residence	Pregnancy context
K05	Fuata nyayo	35-year-old housewife mother of 4. She lives in a one-room semi-permanent house with her husband and children. Referred to Kijani for delivery due to complications. Normal delivery. Babies were admitted for prematurity. One was discharged early to KMC leaving behind the younger one in room A. Mother was in hospital for one and a half months.
K07	Kibera	41-year-old housewife mother of 4. She lives with her husband and children in a one-room semi-permanent house. Passed her expected delivery date and when her labour started early in the morning, she went to the nearest facility, she was referred to Kijani because the baby was breach. She, however, delivered normally. The baby ingested a lot of water and did not cry at birth. The baby was admitted for 5 days (4 days in room A and 1 day in room B)
K09	Kawangware	33-year-old casual labourer, married, and lives with her 4 children in a one-room semi-permanent house. Was referred into Kijani for delivery as a result of high blood pressure. The baby ingested water at delivery. She stayed in the hospital with the baby for a week.
K11	Kangemi	39-year-old business lady, mother of 3. She lives with her husband and children. She was referred to Kijani for delivery because she had high blood pressure. Acknowledges that she started clinic late due to lack of money. In maternity, she was told the baby was preterm with a birth weight of 1.5 kgs. The baby was admitted for 10 days. The baby was moved back and forth from room A to B thrice and finally KMC.
K19	Rongai	27-year-old business lady, mother of 3. She lives with her husband and children. She delivered her twins prematurely in Kijani hospital at 1.2 and 1.1 kgs. She wasn't aware that she was going to have twins. She had been sent for a scan but she did not go. She delivered normally at 7 months. She stayed in the hospital for a month.
K21	Kawangware	29-year-old business lady, mother of 2. She lives with her husband and children. Her baby was born prematurely at 6 months. She considers her pregnancy to have been normal, then one night her water broke at night, she then went to the nearest private facility and that is when she was referred to Kijani. She delivered normally and the baby was admitted for 2.5 months.

T07	Mombasa road	38-year-old single mother of two. She is an office attendant. She underwent an emergency CS having had prolonged labour and the baby was in distress. The baby was admitted for a week in the NBU general ward. She then moved back to her parents' house after delivery in order to get family support and help with the care of the baby.
T09	Umoja	33-year-old first-time mother. She is a sales lady and lives with her husband in a middle-income area. She describes her pregnancy as being smooth all the way. She had prolonged labour and was then taken in for CS. She saw her baby after 24 hours. Tests done showed that the baby had an infection and was therefore hospitalised for a week.
T12	Kinoo	A 25-year-old first-time mother, a business lady, lives with her husband. Her pregnancy was generally smooth. The baby was post-dated and she was then induced. She laboured for long and CS was then recommended. She however delivered just before being taken in for surgery. The baby did not cry and was born with breathing problems. The baby was admitted for 5 weeks.
T10	Westlands	36-year-old married music teacher mother of 3. She lives with her husband in an upmarket area. Having 2 previous scars, she delivered via CS. The baby did not cry at birth and was admitted for a week. For her, this was the most difficult pregnancy.
T13	Langata	A 40-year-old single mother of 2, lives in her parents' house. After a normal delivery, the baby did not breastfeed well after birth and this resulted in the baby having low blood sugar levels. The baby was admitted to the NBU general ward for 6 days.
T17	Ngong	28-year-old client relations officer first-time mother. Lives with her husband. She had a smooth pregnancy until her third trimester when she developed high blood pressure. This prompted admission and emergency CS. The baby was born at 32 weeks and was admitted for about 7 weeks.

### 7.3 Life in the NBU

Data from the narrative interviews contain the reflections of the mothers on their journey and experiences while in the NBU. A broad theme that emerged from these narratives was that of uncertainty. In the sections that follow, I describe the mothers' journeys, illuminating certain sub-themes that characterised the concept of uncertainty that was evident in the narratives of the twelve women.

#### 7.3. 1 Shock and confusion

As much as this study was aimed at eliciting the experiences of the mothers while their babies were hospitalized, while conducting the narrative interviews, my research assistant and I quickly became aware of just how much *what had gone before* mattered. The journey of pregnancy and delivery was an important part of the narrative as it helped them make sense of what happened to them and their baby. While some would ask us if they could begin telling their story from the pregnancy period, we noted that others often made reference to certain prenatal and delivery experiences in their narratives. This indicates that antenatal and post-natal experiences are most likely viewed by the mothers as a whole, with one event being interconnected to the next.

Shock and confusion started for all the mothers immediately after they had given birth. Mothers' accounts frequently contained descriptions of how what was happening was different from what they had expected. Mothers explained that it was difficult to understand what was going on or where their baby had been taken. Some of the mothers were already aware that they were at risk of pre-term delivery and a few had given birth through caesarean (CS). These differences emerged during the mothers' description of their experiences. For 4/6 mothers from Kijani, the early onset of labour was unexpected and they ended up giving birth before term. They described how they were in the midst of their daily routine when their waters broke. They then reported going to the nearest facility where they had been attending their antenatal clinics. It was then that they were informed that they needed to go to Kijani, and soon after reaching Kijani and getting examined, they were then informed that they were in labour. As Lucy describes below, this unexpected onset of labour came as a shock.

*"I even did not understand what was happening to me, I was asleep, it was on a Friday, at around 3 pm, and I realised that my water was coming out, so I rushed to a private clinic that is nearby, and they told me "you just rush to Kijani", and that*

*is how I rushed to Kijani, and on getting examined I was told that I need to go for a scan, the scan revealed that I had a lot of water and the baby is small, I was six months pregnant, they then admitted me for like 4 days and then I delivered. So then you know with that you must get shocked because it is not normal". (Lucy,\_K021 narrative)*

This aspect of shock was also present in narratives of some of the Tausi mothers as they talked about their delivery. One such mother was Tina, she talked about the unexpected events that preceded her birth. She described her unexpected delivery and resulting shock as follows.

*"My pregnancy from the beginning it was quite smooth, my first and second trimester were very fine. Healthwise at all my doctor's appointments I would be told everything is perfect, until when I got to my third trimester. That's when my blood pressure started going up and I was monitoring it but not on medication and then just one day I woke up all swollen up and that's when now I went to the hospital and I was told my BP was just over the roof. So the doctor admitted me immediately and on that very same day, he told me we may have to deliver the baby as soon as possible. Yeah, so things just went from good to worse in like less than a day for me. Yeah, then umm now from there I was admitted and I spent the day in the hospital, they tried to get my blood pressure down and the following day in the morning they took me to the ultrasound to have an ultrasound done. because I had complained at night I couldn't feel my baby moving. Yeah, and they had put me through a lot of medication to bring down the blood pressure. So when they took me for the ultrasound that morning that's when they told me it looks like the baby is not moving and it looks like there is a cord around his neck there is only a heartbeat but there is no movement at all. So they had to take me to theatre immediately. And the next thing I know is I'm in the theatre they are operating on me, and yeah the baby is here. ... you know it's those things you hear but had never really put my mind there. I had never even want like try to find out what happens when a baby comes before time and if it's before time I used to assume that it would be like 36 weeks which would you know mean you still just deliver and you go home with your baby immediately" (Tina\_T17 narrative).*

For all mothers in Tausi hospital and for a few mothers who had developed complications or had undergone a CS in Kijani, babies were transferred to the NBU on their own as their mothers recuperated. These mothers then narrated how they barely got a chance to hold their

babies at birth. They reported being shown the baby by the doctor and being informed of the sex of the baby. They were then told that the baby was being taken for care in the nursery. This was the first point of the mother's emotional feeling of separation, where babies were taken away from their mothers. Using quotes below from a well mother from Tausi and an unwell mother from Kijani, I highlight how these mothers talked about being separated at birth from their babies. They highlighted the length of time it took before they were reunited with their newborns after their own recovery.

Mother B Kijani: *"The baby was very small. I wasn't given the baby. After delivery, I was told this is your baby, a baby girl. She was then rushed to the nursery. I had a problem, I was bleeding a lot, I stayed there for another hour as they were still attending to me. I went to shower and then went later to see the baby"*. (K09)

Mother A Tausi: *"He didn't cry at birth and that is why they took him away to the nursery. So you know as a first-time mother I didn't know where they had taken him to. I thought he was being cleaned and would then be brought to me. So I waited with the hope that he would be brought to me. ...So I waited in my room till the next morning when my husband came at around 9 am and I didn't have the baby. And I told him that I did not know where he was, but I think he was in nursery, I am waiting to be told. Later the doctor came and told me that they were caring for the baby in the nursery but they needed me to go and express milk. And that is when I went to the nursery"*. (T12)

While what was happening might have been obvious to the medical staff, it was clear from the narratives that the mothers were 'lost', having no idea where the NBU was, what happened there or why their baby had been taken to the 'nursery'.

In the following table, I highlight some of their perceptions of the nursery.

Table 7. 2 Mothers knowledge and perception of the nursery

**Views from Kijani hospital**

- K019 *I did not know. I had never seen things like the ones I found in the nursery. Like that machine where the baby is placed inside [referring to the incubator]*
- K021 *No, normally you just hear nursery and you hear that a baby is in nursery, a baby has been taken to nursery, but if you have never been there you wouldn't know what it is. I didn't know, I found myself there and that is when I knew so this is the nursery*

**Views from Tausi hospital**

- T007 *He had been taken to the nursery. But then me I didn't know, I thought that the babies just stay in the nursery, and the baby is brought to you (in your room). He was in the incubator with a balloon oxygen, now he was in a bed and I was like oh phewks. Now I started learning this is a place for sick children. If he wasn't sick, he wouldn't be here. I could have been with him in my, in my, in my whatever, in my ward. That's when I learnt. I was... I don't know, I don't know I can't explain but it was so painful because me I know you go to the hospital, you deliver and you go home*
- T017 *Uh-huh well at first it was a bit difficult, I you know having never been into a nursery or a newborn unit. I didn't know what I was supposed to do and what I was not supposed to do. I didn't know what the nurses want you to do or not to do it was a bit difficult*
- T13 *first, first of all, it was a bit I think I just didn't know what to expect what was happening, in fact, I didn't know what was happening exactly because the only thing I know is just he is here for observation, you know. For them to make sure he is okay then he is going to leave. That's what I knew when I was in the ward and then I walk in there and I look at the baby inside the incubator and I'm thinking he is too tiny he looks too tiny you know. In my head I know I'm leaving very soon I'm leaving with my baby at any you now maybe after the three days that you stay in hospital after delivery or so. So, I would just look at him and... at first you know there want so much information about what is what, because I think also the doctors didn't know what to expect on day one of the baby then from there the next thing is I'm just being told you need to start expressing milk, we need to feed the baby.*



### 7.3.2 Doubts and frustrations; mothering in Limbo

For a mother, being in the NBU with a sick newborn introduced a sense of powerlessness and helplessness. Mothers expressed their frustrations of not being able to give birth and go home with their babies as other mothers would normally do. In their narratives, some of these mothers while reflecting on their experiences expressed frustrations;

*“Now I started learning, this is a place for sick children. If he wasn't sick, he wouldn't be here. I could have been with him in my, in my, in my whatever, in my ward. That's when I learnt, I was... I don't know, I don't know I can't explain but it was so painful because me I know you go to the hospital, you deliver and you go home but it was an experience I don't know. I have learnt something that you can go to the hospital, give birth, you go to the... you get admitted and you can go to the hospital you give birth and you don't go home with a baby. You can go to the hospital you give birth and you all go, yeah I've learned that” T07*

*“That's what I knew when I was in the ward and the I walk in there and I look at the baby inside the incubator and I'm thinking he is too tiny he looks too tiny you know. But then still I'm thinking okay if he is okay I'm sure well manage you know. The doctor says he is okay and good to go home, we'll just leave. In my head I know I'm leaving very soon I'm leaving with my baby at any you now maybe after the three days that you stay in hospital after delivery or so. So, I would just look at him and... at first you know there want so much information about what is what, because I think also the doctors didn't know what to expect on day one of the baby then from there the next thing is I'm just being told you need to start expressing milk, we need to feed the baby”. T13*

The strictly regulated access to the NBU and resulting separation of the mothers of babies in Tausi made them feel powerless. In their interviews, some of these mothers wondered whether their babies would be well taken care of by the nurses in their absence. For some of the mothers in Tausi, these frustrations and the doubts that came with separation were more prominent as they had opted for voluntary discharge leaving behind their baby in the care of the nurses.

*“Yeah, so at least if you feed you wait for another four hours, three hours for him to feed again. And umm of course really you would have loved to just hold the baby throughout. I didn't have a choice”. T10*

*“And the only sad part is that now we were going to be separated from her until when we will get back together. Yeah, that what, what happens then at the, at the nursery? Who will take care of her? How was it going to be done? What is it that is going to be different? Then they said I should, I should take short time with the baby so I should get the, the breastfeeding pump and the, the things for feeding the baby. I was like, my, my baby would not be breastfeeding me. Then even there the, the baby is being handled by the nurses now, the trust, how will I trust all this, it’s the care, is he taken enough care of actually”. T11*

*So after one week, the doctor told me that the baby was still not well and so I would have to leave him in hospital and go home. That I be coming daily to visit and to bring the expressed milk, I refused. I could not imagine doing that. How could I come home and leave the baby behind? No way. I cried and cried and refused. They discharged me on a Sunday after one week. I chose to stay on and the insurance told me that if I chose to stay I would have to meet the accommodation cost because I wasn’t sick it was the baby who was sick. I told them it’s okay, so long as I stay with the baby. So I just stayed with the baby. It was really bad being asked to leave the baby behind, it was a no, to leave the baby after one week? No. T007*

In both hospitals, mothers whose babies were either in the incubator or the radiant warmer expressed their frustrations with not being able to hold and cuddle their babies. The equipment and the treatment introduced a barrier between the mother and the baby, limiting the extent of interaction as illustrated by the quote below;

*“I would hold him but not that much. You could not remove him from there for so long because the baby required the warmth [from the incubator], you know the baby requires the warmth. If you remove him, you interfere with the warmth and he will not get well quickly. So it was better you just leave him inside there. If he was on oxygen too. You would just hold him briefly; you leave him in the incubator for long but you hold him for just few hours”. K19*

For Tausi mothers, it was after getting involved in daily care and when they were able to start breastfeeding and continuously be with their babies that they started to feel attached to their newborns.

*I have been involved in things like breastfeeding, at least you feel good when breastfeeding you feel good when you wash her, when you change diapers at least*

*you start to bond. You hold her she keeps quiet, when she cries you hold her and she keeps quiet. I think this is the time now you become a mother. T018*

In Kijani's KMC room, were stable babies. For the mothers of these premature babies, moving from room A to KMC was an indication that they were moving closer to discharge and this was a source of relief. As explained in the context chapter, the KMC room was also where the Kijani mothers were able to spend all the days and nights with their babies without having to step out for long. Here, they shared the same bed with their babies. For them, being in the KMC room was one of the most memorable experiences because they could now spend all the time on their own beds with their babies as opposed to the constant back and forth movement between maternity ward where they slept and the NBU where their babies initially were as described in chapter 6

*"In KMC I was very relaxed because there you would sleep on the same bed with your baby very well. While at KMC it was just as if I was at home. There was no stress there" K19*

Multiparous mothers of Kijani hospital greatly worried about the wellbeing of their other young children left at home. As explained in chapter 5, in Kijani hospital, mothers stayed in the hospital throughout the baby's admission. These mothers expressed concerns about how long hospital stays interrupted their lives at home. During their hospitalization, the children at home were looked after either by their husbands, relatives or neighbours. Of the two study hospitals, women in Kijani were disadvantaged, lacking the privilege of being able to afford to pay for childcare or employ a childminder. As their spouses were also in informal employment, they could not afford the luxury of taking prolonged leave from work that would enable them to effectively look after the other young children at home, visit their wives daily in hospital and at the same time provide resources for their hospitalised wife and baby. On the whole women in Kijani rarely complained of the absence of their husbands, as they understood they had to work. To keep in touch with their lives back home, these mothers reported that they would talk on phone with their young ones if they had a phone. Once in a while, the other children would come to the hospital with their fathers to visit, however, they would not be allowed to see their new baby brother or sister. These two women from Kijani hospital had this to say about their struggles with childcare:

*“I was very stressed because my child who this one follows is very young. They follow each other. He is two years almost three years now. When I got this one and I was in hospital, I would get phone calls “please talk to George so that he stops crying”, he used to cry a lot “I want my mother”, my concern then was how will I go home? That used to worry me a lot, how will I go home and I have this one here in hospital”.*  
Kijani 019-narrative)

*“He was being looked after by his father, but not that well, even if you look at him after I came back home, no [he doesn’t look okay]. He was then taken to my sisters, and he got sick there, he didn’t like it there, he just used to cry, it therefore forced us to bring him back to his father, and then on coming back again the other issue was that his father had work, he therefore used to leave him with the neighbours. When I came back I found his body had changed. Even when I was in hospital they phoned me that he was sick, I saw a long day [became extremely stressed], I even used to talk to myself, I was feeling as if problems were continuing both in hospital and at home, ahh!! (Kijani 009-narrative)*

Therefore, while for the women in Tausi, the main frustrations and doubts appeared to be linked to separation and not having continuous access to their babies, for the Kijani mothers the doubts and frustrations were more linked to not having access to their home lives and their other young children at home.

### 7.3.3 Powerlessness and tensions

In the previous chapter, while discussing the roles that mothers play in the NBU, I introduced the concept of a “good mother” vs “bad mother” or what the nurses as well as the other mothers considered to be a “good mother”. Good mothers were those who complied and did what was expected. As seen from the quotes below, doing what was expected of them did not always come easily. In both hospitals, one main task expected of the mothers was that of expressing milk. As discussed in the previous chapter, this is something many of the mothers struggled with. While in both hospitals there were no adequate breastfeeding support interventions in place, a key difference was that Tausi mothers had an alternative feeding option. In Tausi mixed feeding was encouraged and allowed. Therefore, unlike for the mothers in Kijani who lacked this option, Tausi mothers could fall back to formula milk whenever they were unable to express without any repercussions. Many mothers complained about having painful nipples and insufficient milk. Despite these challenges that they underwent, Many of the Kijani mothers amidst all the struggles strived to do what was

expected of them. However, in their midst were a few mothers who went against the expected norm. One such mother who initially struggled with this task and therefore failed to comply was Naomi;

*“I even did not....they would insist that I express, but I did not express because I did not feel like.... I knew I had no milk, so I wondered what they expected me to express yet I did not have, I didn't have!” K07*

For some of the Tausi mothers, there were elements of struggle with transitioning from bottled feeding to breastfeeding as some of the doctors instructed. In talking about the expectation to stop giving the baby formula milk, the mother below talked about her frustrations;

*Breastfeeding? Breastfeeding, okay, first of all uhh, I think first of all my milk did not come immediately but it didn't take long. So my baby I think was not getting enough milk. And I remember first of all what they do they tell you to buy the nan [formula milk] just to introduce the baby so that so that the baby doesn't stay hungry. Yeah, so you find that the baby becomes comfortable because with the bottle is faster and then now you want to change to this one that he has to use so much energy pulling. So I went and innocently told the doctor that that uhh the baby drinks formula milk but he doesn't breastfeed. “No nun. This baby has to be, has to become very hungry. No nun, just breastfeed” the doctor responded. I think that is why I stayed for long hours because he was waking up every other time. So, yes, we tried breastfeeding the whole night. And I remember when I was cold [breast feeding room was cold at night] and I was thinking oh God, let them not call me because I can't handle the baby. Let them not... I am just thinking I pray they don't call me, they don't call because I can't carry the baby. T09*

In both hospitals, some mothers had concerns about how their babies were being managed but felt unable to voice these concerns to the staff and felt quite powerless to change management practices. For example, one mother from Tausi, whose baby was being fed via NG tube, narrated how although she was a bit worried about the tube, she did not voice her concerns, taking precautions not to contradict the doctors.

*“At first it was a bit disturbing in fact I was just feeling like maybe the tube is the reason he is not digesting the milk. I mean so at first it wasn't that but uhh with time I just came to, to see okay the other babies are feeding the same way too so it must be the right way uhh I mean it has to work. Umm if I said you know I wanted to*

*suggest like to the doctor let's remove the tube maybe it's the one causing the infection recurrence because the infection reoccurred but then I realized if we don't do that I wouldn't know if he is digested or not because at least through the tube they get to check how much is in the stomach. Yeah so I just figured I just have to let them do their thing at the end of the day and just trust in God that it will work out” T017*

A mother from Kijani whose baby was born prematurely and stayed in the hospital for the longest, (3.5 months) from this cohort, talked about these power relationships/powerlessness and tensions about the norms, procedures, and requests from the doctors like this;

*”So there were some whom maybe the nurse had told you that if a new mother comes in and maybe you have been on the ward longer, and maybe when the nurse is alone let's say at night, so she asks you “Juliet try and help that mother, show her how to feed because she is new”, you show her how to feed or how to adjust the oxygen mask, you find that some of the mothers will listen to you but there were some who will not listen to you. She doesn't take what you are telling her seriously, she prefers to hear it from the nurse or doctor. So for such you would just keep quiet and look at them. So you know there in the NBU what mattered was that you feed your baby so that they add weight, if you failed to feed on time and follow instructions of the doctor you will remain in the hospital for long, but if you do as the doctor says for example if they asked you to take blood samples to the laboratory in Kenyatta you do that, they tell you to put the baby on the phototherapy you do so, you just do as they say. So you know there the person who matters is the doctor, you are the one who needs their help, it forces you to do as they want so that you get discharged quickly, if you don't follow, you will remain there in Kijani forever”. K21.*

For the mothers in Kijani, the daily routine of caring for the baby involved a lot of movement between the maternity ward and the NBU, to fit in with the prescribed feeding schedule and this was very tiring for the mothers. Kadzo talked about these requirements imposed by the hospital regime and reinforced by the other ‘good mothers’ and how it made her feel. She found the regular nudging about going to check on her baby bothersome, but reflecting back post-discharge she appreciated that the constant nudging from her fellow mothers in the NBU was for the benefit of the baby. Even when not needed, she was constantly reminded to go check on her baby and although it was tiring, she conformed.

*“I leave the NBU and go back up again, you see. Another one was Juliet, she would be so much on my case, but what she was doing was okay [not in bad faith]. “Kadzo wake up, wake up stop sleeping the baby is alone”, by then I had no idea how things are [the norm of the NBU]. It forces me to wake up and go. She would even be harsh if she saw you continuing to sleep, she comes even to where you are sleeping, “you go and see the baby, you did not come here to sleep, the baby is alone”.*

When they were discharged home, mothers were often happy to escape the ward environment where there was constant supervision and monitoring under the keen eyes of the nurses and in Kijani that of the other mothers as well. This new NBU environment introduces new dynamics that mothers have to contend with. In the previous two chapters, we saw how the NBU environment also introduces underlying tensions of having to contend with not having the full control of one’s own child. Mothers had to follow the rules and regulations of the NBU.

#### 7.3.4 Fear and anxiety

In this section, I discuss the fears and anxieties reported by the mothers of hospitalised sick newborns. Emerging from these data, are four main types of fear, these are: i) Fear of the NBU environment and machines, ii) Fear of the size of the baby iii) Fear of the procedures that the baby endured and iv) Fear of death.

For these mothers, fear and anxiety emerged as key themes in their stories. These feelings were heightened by the surrounding emotionally challenging environment. The reality of what lay ahead became much clearer on their first visit to the NBU. The reality was that the nursery was a place for babies requiring medical care. In this NBU space were machines that appeared strange to the mothers, adding to their anxiety, the first prominent one was the incubator or the “box” as referred to by some of the mothers. Additionally, some of the babies in the incubator required help breathing and were on oxygen or CPAP machines. Loud beeping noises and occasionally alarms would sound off from the incubators. Some of the babies who still could not feed were on IV fluids. The equipment, as well as the alarms, made many of these mothers unsettled.

*“There was fear, especially the way that machine would make a lot of noise like that” T07*

Seeing their babies in the incubator and attached to machines made some of the mothers anxious. Being unsettled and surrounded by these machines, meant that mothers could not freely carry or hold their babies as they would have wished. They also could not bond freely with their newborns.

*“Shocked, I felt like crying and then they only had pampers and then you can see tubes but it’s not like they were feeding them, it was just in the you see machines and then I’m like so how am I even able to touch my kids when they’re in there. How can I embrace them, how can I hold them, what is going on? I was just puzzled, I just felt tears coming out of my eyes, yeah”.* T20

The size of extremely premature babies was also a source of fear and anxiety. Mothers often worried about hurting the baby. Many of the women in this study had never seen such small babies and this shocked them. One such mother was Peninah. She had given birth to twins, both born with extremely very low birth weights. In her interview she described the experience as scary, she said;

*“I was scared, I feared of how small my babies were, I had never seen such tiny babies like that. The first one was 1.1.kgs the second one was 0.9 kg”.*  
(Peninah\_narrative K019)

Captured in their narratives, were their feelings and thoughts about their presence during medical procedures that their babies underwent. Mothers worried about the further harm that some of these procedures could lead to;

*“I would feel pain in my heart as parent. You would feel pain because this is your baby undergoing these procedures. It was that drawing of blood that made me fear being asked to go to X hospital for some tests. Also the way they shaved my second twin on the head when fixing the IV line, even after the fluid has run out they never used to remove the needle. I worried because if the injection stayed for long it could swell”* K019

Both the staff and the mothers acknowledged that some of these procedures caused them psychological stress. We saw in chapter 6 for example where mothers could not watch the NG tube being fixed for example and voluntarily walked out. In Kijani hospital, mothers often sat by their baby’s cot and therefore observed the procedures if they so wished. In Tausi on the other hand, it was common for nurses to request the mothers to leave the room before a procedure. Some of the mothers such as Hellen below understood being asked to



leave during intrusive procedures but struggled with the request to leave the room during less intrusive ones such as feeding. When talking about being asked to leave the room, Hellen narrates;

*One thing at times I used to wonder okay, why and then there are those procedures that I would okay I was okay moving out like when you know it's something that I know I would watch the baby experience some pain. That one I was okay because I would feel like me being there is also, it also you know has a toll on me but there are those simple things that I would feel like now feeding as in I wouldn't really feel like it's fair to say or for him to say excuse me I need to feed the baby (T017).*

Overlaying everything was the fear of death. Mothers worried about the survival of their hospitalised sick newborns. The newborn unit housed very delicate babies some of whom survival was not guaranteed. Mothers were well aware of the probability that their babies may or may not make it. They observed babies die regularly in the NBU. In Kijani hospital, babies would die almost daily. In both hospitals, the death of a newborn always affected the mood of the other mothers in the ward. This fear of death appeared more prominent at admission and during the critical phase. In Kijani hospital where mothers were continuously present, they came face to face with death much more regularly, the fact that dead babies would also be placed on the ward for some time also worsened the reality of death and their narratives were characterised with reports of almost losing hope. Below are some of the quotes of these mothers talking about their experiences and fears of death in Kijani hospital.

*"The days in the NBU are long, but what can you do? there it just forces you to be courageous, because you can wake up one day and find that a child who has been with you in ward, a child of someone you have been with in the ward, you wake up and find that that child has died. That makes you lose hope you become stressed just like your friend, that day will be spoilt, you will have a bad day" (K021)*

*"Inside there [in the NBU] when I got there that is when I developed a lot of anxiety, you know you just stay there like this and you see someone's baby die and then you start worrying, you understand how in there is?" (K019)*

*"When my baby was still on oxygen, I used to feel so bad, I used to feel even as if I had lost strength, at times I even wished ... not even when he was only on Oxygen but when he was in the incubator, times would reach when his condition deteriorated , you see, at times you go and find that he is even struggling to breath, ahhh, as in at*

*times would come when I just start crying, I lose hope at times, I ask myself will this one become a child [survive], the way he was so tiny and you had never given birth to such a small baby before, that thing really used to stress me a lot. It was tough and I asked myself whether I would get through this, but it reached a point where I just gathered courage/strength, it reached that point because that place where we were, we were many, and at times I would really be in deep thought, at times I thought that maybe my baby will die or will not grow, and at times babies of those who had been in there with you would pass away, one time you meet them and you find they crying so you ask yourself why are they crying? The baby has died another one the baby is just admitted like this” (K011)*

There was also fear created by a lack of information. This lack of information made the mothers feel powerless. While talking to me or amongst themselves, some of the mothers expressed their desire to be provided with more information regarding their baby and treatment procedures, however, from my observations, mothers rarely requested for more information from the staff. The lack of information added to their anxieties related to the wellbeing of their baby. Mothers yearned for rich information, wanting to know more about their baby’s condition and treatment. Mothers narrated how stressful it was not to have a clear picture of what exactly was happening with their newborn, they explained;

*“So from there that is when I was told that the baby is preterm, and even though he was preterm and you know I wished that they provided me with more information about what that was, and whenever I asked them to tell me what problem the baby had, they tell me the baby was preterm, just that, end of story, nothing more than that. And then I did not know that if he was preterm then why was he on oxygen, that is one thing I have never understood till now”. K011*

*“Fear maybe they were not giving me all the information, fear of what will be happening. You know? If she’ll make it, you know, that time when you are being given vague information, as long as it is not first-hand information, you’ll not necessarily trust it”. T019*

### 7.3.5 Anticipation and excitement

Mothers were happy about their babies getting better. Anticipation towards discharge was a key theme to emerge from the narratives. Because of the fear of death, separation from family, many mothers in Kijani thus looked forward to their babies transitioning from NBU

to home. In Kijani hospital, a move from room A meant that the baby was getting better and symbolised transition towards discharge. As the babies got better and transitioned to other care spaces, so the mother's emotions changed. As presented in chapter 5, the NBU had different transition points, i.e. critical and stable phases. Each of these phases was often characterised by different emotions, starting from extreme fear, worry, and anxiety to a feeling of calmness, collectedness, and tranquility. This shift in emotions was characterised by stronger connection, bonding, and attachment to their babies. These mothers longed for discharge and eventually going home with their healthy babies. The journey in the NBU was therefore marked by transition points, not just in the physical space they occupied but also in their emotions.

**Kijani mother O21** *“Even on that day I was just praying and asking myself what time Dr. X would arrive to allow me to go to the other side because there in side A, ehh no, I had been sent to KNH for an echo and I had brought back the results, the following day Dr X came and looked at the results and she said that the baby was found to be okay, the baby did not have a problem, she can breathe on her own, and then DR X asked me so what are you still waiting for here, go to KMC, and I went to KMC, I was very happy by the way to leave side A, because you reflect back on what you have been through since you got the baby, ehhl!, there in side A is a no, once you leave side A and go to KMC or you go home, you are very happy”.* K021

**Tausi mother 017** *“I was so excited. [[M: Ehee] I was in disbelief at first. I felt like the doctor is trying to prank me because he called me and he just asked me do you want me to discharge you today or tomorrow. And I told him if you are discharging me it's right now. I'm not spending on more day you know coming here. And I was not even ready to go because I had been ready like an earlier time and then they had to hold back because I don't know some tests the baby was not... uhh they wanted to make sure he is looking okay and everything. So that day I got really discouraged and when I did that I just told myself I'll just be going there like someone who is not being discharged so that I don't get my hopes too high and then I get all you know broken down when the day ends and I'm not discharged. So when he told me he is discharging me I was so excited I was so happy [[M: Mm-hmm]] I even you know at that point I didn't even want to know do I have everything for the baby do I not have everything when we get home how will know I just wanted to be discharged and see myself handling my baby at home”.* T017

## 7.4 Coping with uncertainties in the NBU

Having described the fears and anxieties that mothers of hospitalised sick newborns endure on a daily basis, I now move on to describe some of the ways that the mothers adopted to cope with the hospitalization of a newborn. Two levels of support emerged from the data.; one from within, at the individual level and a second from supportive relationships.

### 7.4.1. Individual-level mechanisms

These include behavioural actions taken at a personal level by the mothers in order to cope with the stresses of the NBU and with the hospitalization of their newborn. Emerging from the narrative interviews were two main individual-level strategies, detachment, and Faith.

#### 7.4.1.1 Detachment

Detachment here involves the reaction of keeping away from the NBU, being withdrawn and indifferent towards their newborn. While their babies were still in a critical condition, for some of the mothers' response to their fear and anxiety was being distant and withdrawn. The mothers exhibiting this detachment shied away from performing tasks such as feeding and observations. Some of the mothers were rarely present in the ward as a result of the extreme fear that they underwent. These mothers, while still admitted in the hospital, mostly kept to themselves in the maternity ward or in their rooms. This kind of response was most common with mothers whose babies were critical or very premature.

In their narratives, such mothers reported they kept away not because they did not care, but rather because they could not cope easily with the possibility that their child might not make it. Additionally, mothers of premature babies were frightened by the size of their babies. This detachment links back to the notion of being perceived as a bad mother where such mothers were deemed or considered uncaring and not concerned about their babies by the staff as well as other mothers. However, it appears to be an important coping response for mothers of very sick babies. By being away and creating some sort of emotional barrier between them and their sick baby until a time that the baby improved, was a common response exhibited by some of the mothers as the case below depicts.

*“When the baby was still on oxygen, I felt bad. I feared seeing him. I was fearing, I had to wait. But when the baby was moved from the incubator to the cot, I felt better about that. Yeah. In fact, I asked them to give me the baby I stay with her*

*here, but according to their policies they don't okay. They have to observe the baby from the nursery" T07*

#### 7.4.1.2 Faith

Turning to prayer and entrusting the baby to God was also an action that the mothers resigned to. Mothers prayed daily for their babies and their faith gave them comfort and strength to overcome the challenges that they faced. Whenever the condition of the baby deteriorated, mothers broke down as presented in the previous chapters, in their narratives while talking about such moments, the mothers explained that they turned to God, saying a prayer for help and entrusting the baby to God for healing. Some of these mothers narrated as follows;

*"You feel bad, but what can you do, I thought I was the only one with a small baby but we were many, and that encouraged me, I then just told God now it is up to you asked God to help me, because you know there were those who were also there who had come and slept there with their baby for two days and the baby passes on or they just come and soon after the baby dies, so there is a place where you just have to be strong/encourage yourself" K007*

*"Because I could not walk to the nursery, I had to wait until the foll... I went into, into theatre at around seven, (6:30 pm at around 6:30 pm), I saw him the following morning at seven. About 7:30. Yeah. You know, me I just kept on praying. It was very difficult because I was very anxious, I just wanted to see the baby and make sure there was a baby first. Because the last time he was leaving the theatre he was not fine. But I couldn't walk, and still because I was still numb up to about uhh uhh 2 a.m. Then after that, I was just on drips mostly, you know there was so much happening on me as well". T010*

#### 7.4.2 External support mechanisms

As well as drawing on internal coping mechanisms the mothers also drew support from relationships with people surrounding them, who not only offered support but much needed encouragement. I classify these supportive relationships as either lay or professional support mechanisms.

##### 7.4.2.1 Lay supportive relationships

Family, friends, and other mothers in the NBU emerged as important sources of support for mothers whose babies were hospitalised in the NBU. Family for women in both hospitals

included husbands, sisters, brothers, in-laws, and own parents. In both study hospitals, family members and friends visited the mothers. In Kijani hospital, they brought food and other needed supplies for the mother. As described in this chapter, for multiparous mothers with other young children in Kijani, they provided the much-needed help with the care of the other children left at home. They came in very handy, especially with long hospital stays. For mothers in Tausi, their husbands were able to visit both the mother and the baby daily before the mothers' voluntary discharge. This was not the case for the mothers in Kijani hospital as discussed in *section 7.3.2* above.

As discussed in the context chapter, mother-to-mother peer support networks that developed in the NBU, especially for the case of Kijani hospital, was a very important source of social and psychological support network that mothers heavily relied upon during hospitalisation. Additionally, knowing they were not alone in that situation was also encouraging for the mothers. These informal relationships were very important and for some of the mothers extended beyond the NBU as shown by the narratives below. Using the excerpts below from the narrative interviews, I show how mothers talked about these lay supportive relationships.

*“You feel bad, but what can you do, I thought I was the only one with a small baby but we were many, and that encouraged me”. K011*

*“A lot, in fact it is him [husband] who first encouraged me. When I gave birth the baby was very small. So I called him after I had delivered, and he came the following morning, he came and saw the tiny baby, and he told me that this one will grow, and I asked him are you sure this one will grow and he told me to be strong that the baby will grow, as in he really encouraged me and I got convinced that the baby would grow. You know there are some men who will and come and tell you that this one will not grow, doesn't encourage you or does not even come to visit. My husband used to come and if he doesn't he would call and inquire on how the baby was, he encourages you such that you have hope that the baby will grow, yes. My sisters would also come visit, my aunt, many people would also come to visit, many church members”. K021.*

#### *7.4.2.2 Professional supportive relationships*

Staff working on the NBU also played a key role in supporting the mothers in the NBU. In both hospitals (albeit to a different degree as discussed in chapter 5 and 6) nurses, clinicians,

as well as nutritionists, offered mothers help with tasks. They taught the mothers how to care for their babies, counselled, and encouraged the mothers.

Mothers recognised the personal qualities of the staff. They appreciated these personal traits and soft skills of the staff whenever they talked about the concerned nurses and doctors. Mothers in both hospitals were appreciative of the support that these “good” nurses, nutritionists and clinicians accorded them. They were appreciative of their efforts and in their narratives talked about their wish to continue keeping in touch with these staff. The good nurses and doctors were described as having qualities such as good communication skills, good/clean heart, helpful as seen in the following quotes,

*“The NBU nurses are very good, especially one with an accent from the xxxx, I like her very much. I did not feel that any of them had a bad heart. In fact, you got used to them and could even request them to keep an eye on your baby to allow you to go lie down a bit and they say “I even tell you to go these children are mine”. You see they have a clean heart a caring heart”. K09*

*“Aah the nurses were very okay, I didn’t experience anything bad with them, I had a nice relationship with them till the time I was discharged, even when I go back I still feel they were good, you know it is just the way you relate with them, they would tell me do this I do, and by that when the nurse or the doctor tells you to do something and you do they are happy, but if they tell you to do something and you ignore then that is when things will be bad. On the first day there I can’t lie there was this nurse called ..... and this other one I can’t remember his name, they are the ones who helped me especially on the first day, the female nurse helped me on the first day, this baby was so small, so she she helped me by wiping for me the baby and then showed me what to do. There are some nurses who also encourage you, they tell you ahh if you look there are some other babies who were here, these babies who came here very small and they have grown, at times some of them look after your baby for you when they see you are too tired they tell you to go and rest, and when you come back you find the baby doing just fine, they recognised when one was very tired and sleepy and could encourage you to go and sleep, and that made me really happy. K21.*

## 7.5 Getting home

All the mothers looked forward to finally getting home with their babies and being rejoined with their families. Mothers were equally overjoyed by getting back home to the privacy and comfort of their homes. When talking about the joy of getting back home, two such mothers narrated;

*“Now you know here is home, now you have come home, you are used to your home, it is not like Kijani, you are now happy you have left the prison. There it is like a prison, where you are just stuck in one place like this, and you had to share beds even four people in one bed, so you just had to agree with each other, and take turns, but then you find that you still can't sleep, you are many”* K021:

*“Umm the first few days were very interesting umm it was really exciting I just found myself staring at him all the time. Even when you are sleeping I would just be there and I it really felt good because for me I was just wondering would it really ever get to this point you know where I'm home with my baby and you know we are just doing everything from here and he is all okay. It was... for me it was just one some of the best moments ever”* T07

All the 12 women participating in the narrative interviews reported that they were now comfortable with caring for their baby at home. They appreciated having been tasked with feeding, bathing, and changing the diapers of their babies in the hospital. By the time they got home, they had grown in confidence and reported that they could easily perform these tasks on their own.

Despite the return back home being filled with joy, some of the mothers had subtle moments of worry. Worry of what if something went wrong that required medical attention, whom would they turn to for help? While in the hospital they were surrounded by nurses and doctors whom they alerted whenever they noticed a problem with their baby. Kijani babies were expected to be taken back for weekly review visits for a period of six months post-discharge. It was at these visits that the mothers were able to report any experienced or observed issues.

*“I was worried maybe the one who was 1.5 kilograms, how will it be? But I just covered her, kept her warm and every time I used to go back to hospital at that time the strike had not yet started. The doctor used to look at how she is progressing”* K05.



*“You know now you had been used to for example anytime the baby had a small problem like this you would rush to the nurse or doctor, so I would ask myself, what if she gets a problem ..., so when you get home, so I was worried that maybe the problem would arise if it did who or where would I run to, but I have not experienced any problem so I am just grateful”. K021*

Tausi hospital, on the other hand, did not have the scheduled weekly appointments. The follow-up review date was given by the paediatrician who was seeing the baby. These were either in the hospital if the baby was being seen by the hospital doctor or at the specific paediatrician’s clinic. As discussed in chapter 5, each baby was treated by a different doctor. At discharge, it was common for mothers from Tausi hospital to phone their doctor's post-discharge in case they noticed a problem with the baby. At discharge, these mothers reported that their private doctors provided them with their personal phone numbers through which they could easily reach them if need be. Below are some of the mothers talking about their worry and how they arranged to obtain help from the doctor post-discharge;

*“Maybe the only worry would be okay in the newborn unit it is easier for them to say the baby is not looking well you know they would spot some things that maybe I wouldn’t or I would worry about it and they tell me this is normal so I would be like okay when we go home, what happens when the baby now becomes sick or something happens and you know like he is he is maybe throwing up would I know if he is sick, if its normal throw up if it’s you know there are all those things and worries about his health. But at the end of the day I just told myself uhh I’m sure I will manage. What I told the doctor is I need you to guarantee me that I can put you on speed dial even if it’s at midnight, that you will answer my call and tell me what to do next in case there is an emergency. He agreed”. T017*

Challenges with the change in environment for the baby is something that mothers across the two hospitals complained about. The heat in the NBUs was regulated, being a ward setting, the lights were on all the time and visitors were regulated. Mothers acknowledged that their babies had been used to the warmth and the light of the NBU. They thus tried as much as possible to keep their babies warm at home.

*“I did not experience any difficulty, the only problem, you see they had trained me on how to care for the baby at home, I didn’t find any challenges with that, the only problem was the light and cold, you know even now the weather has changed and that is the main problem. At times it is very cold forcing you to cover him up with*

*layers of clothes, at times he has difficulty breathing, if the room is not so warm you notice he starts to sniff, things like that”*. K011

*“So on the first day is when I experienced some problem, because while in the hospital the baby was used to that heat, you know that heat? So every time I would feel cold I would cover him up though he would be uncomfortable but I just used to feel that I need to give him that warmth. You see there in the incubator was warm, especially if you go to the KMC room there is a lot of heat. I used to wonder about how my baby would adapt to the weather at home. But he has done well, he is okay”*  
K09

One of the mothers talked about experiencing intense psychological trauma immediately post-discharge. Because of the fear and anxiety, she underwent in the NBU, she wasn't able to sleep well for a few days following discharge. She struggled post-discharge and resorted to moving back to her parents' home immediately after discharge. She wasn't confident that she would manage on her own. By the time we were visiting her at home, she had adjusted well and reported that both her and the baby were okay. This is how she narrated her post-discharge experience;

*“It was bad. I knew it was bad. Yeah, you see I was telling her we have a WhatsApp group so I know what I'm going through, I know what that was because there was another lady in the same WhatsApp group. She went through the same and she lost her baby. So I know what it was, so I was very afraid, very afraid. In fact, even after that (after discharge) I was having nightmares. I was thinking it was the anaesthesia the one they inject during the CS. But it wasn't that. My doctor told me it's because maybe I was traumatized. When I was sleeping in bed I was kind of getting something like a shock, feeling like I could fall off from the bed. And then I felt as if something was strangling me in my sleep. I don't know what it was. Staying in hospital and getting scared of the hospital, staying in hospital and having a baby in the nursery traumatised me”*. T07

At home, they also now had to deal with controlling visits for their babies. Having come from the NBU, mothers especially of the premature babies were keen to ensure they limited the number of people who had contact with their babies. Many reported that their kin who visited understood that these babies were delicate and needed to be kept warm and isolated.

At discharge, some of the doctors also advised mothers to avoid having too many people visiting the baby.

*“Well as I was leaving the hospital one thing that the doctor told me is to avoid like crowds in the house or having the baby you know, having so many people in the house because this baby is too fragile. So I know it’s really hard to stop people and tell them don’t come and all that, but what I’ve, what I’ve... I think it’s just a coincidence guys have been so busy. Guys have just been so busy and I just keep thanking God. So the only person who’s managed actually to come and see him is his grandfather, now my dad. Who happened to be in Nairobi with my sister and my brother”. T017*

Just as it was while they were still in the NBU, family members and friends continued to be a good source of support for these mothers even after discharge. One such mother received support from her father and siblings, she says this about her father;

*“.. and he said okay, let me drop by and, and see you so when he found out I’m alone he said okay. Let me leave you with these two to help you do the housework. And uhh also not for you to be so lonely yeah. So that’s how they ended up here for the holiday. But otherwise, no one else has been here. Yeah. So we are, we are grateful now that we are buying time until he’s at least more grown”. T017*

## **7.6 Summary and discussion**

In this final results chapter, I have drawn on the narratives of 12 mothers whose babies were born and admitted immediately to the NBU in Kijani and Tausi hospitals. I have presented their narratives of their emotional journey and their experiences while their babies were in the NBU as well as their immediate post-discharge experiences. Despite having different social and economic backgrounds, the journeys of these women in terms of their experiences were very similar. These data illustrate that these mothers’ journeys always started with feelings of shock and confusion, brought about by the uncertainty of not knowing what lay ahead as well as doubts about the wellbeing of their baby. For many of these mothers, the birth of their babies was unexpected, this together with not knowing exactly what the “nursery” was and what was expected of them further intensified these feelings of shock and confusion. These findings are not unique to this study. Premature deliveries and the admission of a newborn baby causes a great level of emotional distress for the mothers, whose main concern is the survival of their baby (Davis et al., 2003; Fernandez Medina et al., 2018; Heidari, Hasanpour, & Fooladi, 2012; Herbst & Maree, 2006; Muller-Nix et al., 144

2004; Ncube, Barlow, & Mayers, 2016; Veronez, Borghesan, Correa, & Higarashi, 2017; Watson, 2011). In a study on American Indian mothers' perceptions of parenting their premature infants, Brooks and colleagues found that the mothers of the premature babies felt unprepared (Brooks, Holdtich-Davis, Docherty, & Theodorou, 2016), a feeling that was commonly emerged in the mothers' narratives in this in this Nairobi study.

Following the initial shock and confusion, the mothers across the two hospitals in my study narrated that while inside the NBU, they struggled with fears and anxieties in relation to the condition of the baby; the size of the baby; as well as the medicalised and unfamiliar NBU ward environment and medical procedures that the baby was exposed to. These findings support the conclusions drawn by other researchers and findings from HICs which have found that having a hospitalised sick newborn can cause significant fear and anxiety (Tolhurst et al., 2008; Veronez et al., 2017). Concerns about the condition and size of the baby have been found in studies on mothers' perceptions of the care of premature babies in HICs. In their study, among 78 mothers of very premature babies in the Netherlands -, Meijssen and colleagues reported that half of the mothers expressed negative feelings about seeing their baby at first. These parents reported feelings of fear especially with regards to how small the baby was and the baby's condition which they admitted resulted in feelings of alienation (Meijssen et al., 2011). Parents of critically sick neonates in a study conducted in Switzerland reported experiencing difficulties in dealing with the babies' condition and prematurity (Muller-Nix et al., 2004). Other studies in HICs have found that parents find it hard to cope with the mechanical surrounding of the NICU (A. N. Johnson, 2008). Evidence has shown that these fears and challenges with regards to the babies' condition as well as the medicalised NBU environment impede mother-baby interaction as well as skin-to-skin contact which is important for future developmental outcomes (Wigert, Berg, & Hellstrom, 2010; Wigert et al., 2008).

Despite the emotional experiences of the mothers being very similar across the two study hospitals, I did note a difference in terms of the concerns that mothers expressed about a long hospital stay. This difference in concerns was associated with differences between the hospitals in their practical norms of care; norms of care that meant that mothers in Kijani had to stay in the hospital throughout the babies' admission while many of the Tausi women were encouraged to go home. As a result, the Kijani mothers expressed a lot of concern about what was happening at home, particularly if they had other children, while in contrast, the Tausi mothers were concerned about how their baby was being looked after by the nurses when they weren't present. As discussed in the previous chapter, these differences in the

practical norms of care are driven by an underlying inequity in service provision between the hospitals with Kijani having insufficient nurses to undertake all of the tasks in the NBU so the mothers have to take on some of these tasks. The greater economic capital of the Tausi mothers provides them with access to more professional care (nurses) but unless they have sufficient funds to pay for a private room it also constrains their ability to be close to their sick baby.

For the Tausi mothers, this then resorted to emotional tensions and feelings of separation and powerlessness especially as they had to transfer the care of their baby to the nurses. Similar findings have also been reported by studies conducted in HICs where the babies are separated from their parents. Mothers leave the hospital without their premature or sick baby leading to a feeling of separation. Hospitalisation of newborns especially in highly medicalised settings often leads parents to feel powerless and helpless. (Hall, Kronborg, Aagaard, & Brinchmann, 2013). By contrast, in Kijani the mothers are unable to leave the hospital so while they were close to their baby they were having different stresses, they were worried about what was happening at home and how a long hospital stay may be affecting this. While in hospital, and because they could not afford to pay for a childminder to look after their other young children, they narrated how their husbands then had to balance between caring for their children at home, going to work, visiting them in hospital. To do this, mothers narrated how many at times these babies were left unattended or under the care of neighbours and for some with a close relative living nearby. Some of these women narrated how such babies who might have been taken to live with a relative ended up not coping well and this the mothers narrated caused them additional concerns. These data thus show that long hospitalisation affected both mothers of Kijani and Tausi as it led to different sources of additional concerns outlined above.

In their narratives, mothers in Both Kijani and Tausi expressed their fears of the machines. They narrated how these machines made it difficult for them to hold their babies as much as they would have wished to, contributing to feelings of separation and absence of emotional closeness. Such experiences have been reported in several studies undertaken in the NBUs of hospitals in HICs. In their Canadian study examining the experiences of mothers whose babies required the delivery of supplementary oxygen, Cervantes and colleagues observed that the technology prevented the mothers from holding their babies adding to their stress and anxiety (Cervantes, Feeley, & Lariviere, 2011). In a review of studies of closeness and separation in neonatal intensive care, Flacking et al. also relate these feelings of separation to the physical distance between mother and baby as well as the absence of emotional

closeness, which they suggest is vital for early bonding and attachment (Flacking, et al. 2012)

In their narratives, some of the mothers from the two study hospitals expressed detachment as a coping mechanism. This was evident especially among some of the mothers of the very critically sick babies. The narratives of the mothers from both hospitals contained repeated mentions of the fear of death, leading to feelings of powerlessness. As a result, some of the mothers said they became ambivalent and detached from their babies. These feelings of detachment have been reported in other studies. An Australian study by Fenwick and colleagues, for instance, observed that mothers of babies in NICU demonstrated ambivalent feelings and that they struggled to attach to babies whose positive outcome was not certain (Fenwick, Barclay, & Schmied, 2008). In my study, many of the mothers talked about turning to faith or God which might also symbolise a lack of confidence in their own agency and a way of dealing with the unknown. These ambivalent feelings amongst mothers of hospitalised sick newborns as well as turning to religious beliefs as an important coping resource was also reported in the Botswana study by Ncube and colleagues (Ncube et al., 2016).

Data from the mothers' narratives has highlighted the importance of positive and supportive relationships within the NBU. In Kijani, the mothers' community was key in the establishment of mother peer to peer support networks which were lacking in Tausi. In both hospitals the importance of the soft skills of the staff which included empathy, good hearts, being helpful and having good communication skills were frequently mentioned in the narratives and highly appreciated by the mothers. Family and friends also emerged as key support systems for these mothers both inside and outside the NBU. Ncube and colleagues in their study of experiences of mothers of preterm infants in Botswana found that having supportive staff as well as informal support from family and other mothers on the ward helps mothers cope better. Additionally, positive partnerships with staff enabled mothers to overcome their fears which might impact their emotional connection with their babies (Ncube et al., 2016). A study by Fisher and Broome of parent provider communication during hospitalisation in the US also made similar observations in relation to communication, interactions and relationships between providers/staff and parents. They conclude that giving information to parents through caring and inclusive approaches is important. They further suggest that establishing interpersonal connections, nurturing relationships and identification of specific behaviours are key to building and sustaining better communication in the ward. (Fisher & Broome, 2011). These suggestions they

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propose all speak to and relate to the strengthening of core principles of FCC of partnerships and communication with parents identified in chapter 2.

Across the two study hospitals, mothers narrated about how they looked forward to eventual discharge and going home but also reserved some fears. Black and colleagues conducted a retrospective secondary analysis of qualitative data previously collected from narratives with mothers of medically fragile preterm infants in the US. They observed in their analysis that these mothers looked forward to eventually leaving the hospital and taking their baby home (Black, Holditch-Davis, & Miles, 2009). While the mothers in my study did look forward to going home, following discharge, mothers from the two study sites talked about their worries about the change in the environment for their baby. Some of the Tausi mothers reported fears about transitioning to caring for their babies alone away from the nurses. Similar observations were made by a study conducted in Spain which also reported ambiguous feelings of joy and fear among mothers at discharge (Granero-Molina et al., 2019). All the mothers from Kijani and Tausi worried about keeping the baby warm in a controlled environment. In their narratives, mothers appreciated having been involved in the care of their babies.

Apart from narrating their fears and anxieties, the mothers involved in this study also appreciated some of the nurses and doctors who cared for their babies and whom they reported offered them the much-needed support during the hospitalization. They described these staff in their narratives as being helpful, having good hearts and caring. What these findings indicate is that there is a need to put in place strategies for helping mothers cope better with the hospitalization of their baby. In HICs, several strategies have been put in place to help mothers cope better (Staniszewska et al., 2012; Westrup, 2015), some of which focus on building these communication skills of the nurses. In the next chapter, I discuss what these findings mean for FCC and quality improvement strategies for newborn care in LMICs.

## **8. SUMMARY AND DISCUSSION**

### **8.1 Introduction**

This thesis aimed to examine the roles, experiences, and perceptions of mothers of hospitalised sick newborns in two Nairobi hospitals. Using an ethnographic approach, my study examined the day-to-day lives of mothers on the ward and their experiences during the hospitalization of their baby. I also examined immediate post-discharge experiences for a sub-set of women. This methodological approach allowed for a holistic interrogation of the roles and experiences of the mothers of hospitalised sick newborns. The findings from this exploratory descriptive qualitative research serve as a first step towards providing insights into what is important to the mothers of hospitalised sick newborns in Kenya. Understanding the experiences of mothers with a sick newborn in an LMIC context is a very important starting point for developing quality improvement strategies that put families and their needs at the center of care provision (Celenza et al., 2017). The WHO and current global debates surrounding quality of care now recognize the importance of patient experiences and family-centered approaches to care provision, therefore, LMICs studies that focus on the patient/parent perspective are a vital step towards attaining these objectives. This study has provided key findings that shed light on the fears, anxieties, and struggles that such mothers undergo during the hospitalization of their baby.

I examined mothers' roles and experiences guided by the key principles of family-centered care (FCC) of; information sharing, dignity, and respect, collaboration, and participation. The Institute of Family Centred care defines FCC as "*an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial partnerships between health care professionals, patients and families*". As presented in chapter 2, although defined differently by various scholars, the key principles guiding this philosophy of care are universal/standard (Jolley & Shields, 2009; Mikkelsen & Frederiksen, 2011; Shields et al., 2006). As an approach to care, FCC aims to provide care for sick newborns that promotes provider-parent partnerships and care in an environment that is responsive to the individual needs of the parents (Gooding et al., 2011; Jolley & Shields, 2009). The core tenets of FCC may encourage maternal involvement in the care of their hospitalised babies which may be linked to better outcomes for the baby and positive experiences for the mother.

The literature review presented in Chapter 2 placed the implementation of FCC in the historical and global context, while the document review presented in Chapter 3 demonstrated the context of health care and maternal and neonatal health (MNH) policies



and guidelines in Kenya. Chapter 4 provided details of the methods used and the sites in which the study took place. In Chapters 5 and 6 I described the context of newborn care in the two study hospitals, the roles played by mothers of the hospitalised sick newborns in the two hospitals as well as their practical experiences. In Chapter 7, I presented the post-discharge narratives of a selection of mothers about their experiences while their babies were in the NBU and immediately post-discharge. In chapter 7 I also described how the mothers cope with the challenges of having a hospitalised sick newborn.

In this final discussion chapter, I provide a summary of the key findings in relation to the objectives of the study and discuss key emerging themes in relation to the broader literature. The chapter has six main sections. In section 8.2, I discuss the key findings and present my revised conceptual framework. In the following section (8.3) I draw on the key themes from this study to critically analyse what they mean for care improvement strategies and FCC in LMICs. In section 8.4, I discuss the strengths and limitations of the study while in section 8.5 I present the study recommendations. In the last section, 8.6, I provide a brief conclusion.

## **8.2 Summary of key findings**

In this section, I provide a summary of the key findings from my study in relation to three of my objectives:

- i) to describe the characteristics, structures, and environment in which inpatient newborn care is provided in the two study hospitals;
- ii) to explore the involvement of mothers in the day to day care of their hospitalized newborns in the two study hospitals;
- iii) to elicit the experiences of mothers of having a baby admitted to inpatient neonatal care in the two study hospitals.

These findings are shown in table 8.1.

Table 8. 1 Summary of key findings

<b>Objective</b>	<b>Summary of Key findings</b>
Describe the characteristics, structures, and environment in which inpatient newborn care is provided in the two study hospitals	<p>A striking contrast in the ward context (layout, ambiance, equipment and staffing levels) between the two study hospitals.</p> <p>Observed neglect in the conditions/state of the ward in the public hospital. Compared to Tausi, faulty equipment in Kijani hospital was not promptly repaired, the ward was only cleaned once a day and was often smelly.</p> <p>Variance in the patient volumes that each of the two study hospitals receives. High patient volumes in the public hospital led to lower nurse to baby ratios as well as sharing of incubators.</p> <p>Difference in the cost of care in the two hospitals.</p> <p>Difference in the social and economic backgrounds of the families seeking care across the two hospitals. Mothers in the public hospital had less social and economic capital compared to mothers in the mission hospital.</p>

<p>Explore the involvement of mothers in the day to day care of their hospitalized newborns in the two study hospitals</p>	<p>Mothers were involved in the care of their hospitalised sick newborns in both hospitals. However, there were key differences between them.</p> <p>Initiation of a mother’s involvement in care varied by the hospital: Mothers in Kijani hospital were engaged in providing care almost immediately compared to the mothers in Tausi whose involvement in care was a carefully managed process that happened over a number of days.</p> <p>Learning how to care: There was evidence of strong informal peer learning among the mothers in Kijani. Mothers taught each other and assisted each other with the tasks. In Tausi, more structured formal learning provided by the nurses was in place for the mothers.</p> <p>Level of involvement in care: In Tausi, care of the critically ill babies as well as premature babies was more highly medicalised. Care of the baby during the initial 24hrs and in the critical phase was left to the nurses. Mothers never involved in NG tube feeding.</p> <p>These differences most likely arise from necessity; a consequence of understaffing in Kijani.</p> <p>Being involved in the care of their sick newborn aided these mothers to transition into motherhood.</p>
<p>c) Elicit the experiences of mothers of having a baby admitted to inpatient neonatal care in the two study hospitals</p>	<p>Having a hospitalised sick newborn was often marked with fear and anxiety. All mothers worry about their baby’s condition and outcome.</p> <p>Long hospital stays affected the mothers as it disrupted their lives. But the source of tensions with long hospitals stays varied. For Kijani mothers, their additional worries were about their other children and lives at home while for the Tausi mothers they worried about leaving their baby behind in the hospital.</p> <p>Separation from their baby and lack of information added to the mothers’ fears and anxieties.</p> <p>Mothers had different coping strategies in the hospital.</p> <p>Despite having more social and economic capital, mothers in Tausi faced social isolation. The peer support network coupled with mandatory long hospital stay facilitated the emergence of a mother’s community in Kijani.</p>

Drawing mainly on my observations, I was able to describe the context of care in the two study hospitals. My research assistant and I spent long hours in the two NBUs conducting observations. These observations made it possible to compare the context of care between a better-resourced hospital and a less-resourced hospital. Through these observations, I was able to identify challenges facing the public hospital in Nairobi, some of which have been reported in other studies (English et al., 2004; G. Irimu et al., 2018; G. W. Irimu et al., 2012; Kimathi, 2017; Miseda, Were, Murianki, Mutuku, & Mutwiwa, 2017; Nzinga, McGivern, & English, 2018). Specifically, the challenges commonly reported to affect the public sector are; understaffing (Miseda et al., 2017; Wakaba et al., 2014); lack of equipment (Nzinga et al., 2018); neglect (Nyongesa, 2013); overcrowding and lack of resources (Mishra, 2001). Of the two study hospitals, patient volumes vs. staffing ratios in Kijani still fall far below the conditions recommended by the WHO and those found in high-income settings. WHO recommends a minimum threshold of 2.28 doctors, nurses, and midwives per 1,000 people (WHO, 2016). The situation in Kenyan public hospitals is not different from that observed in other sub-Saharan countries, where high patient volumes and understaffing have been reported in several studies (Chankova, Muchiri, & Kombe, 2009; Jaeger, Bechir, Harouna, Moto, & Utzinger, 2018) . Further, the nurse to baby ratio especially in the public hospitals was low in contrast to what is observed and recommended in HICs. In the US for example, the recommended nurse-to-patient ratio in a critical care unit is 1:2 or fewer at all times, and the nurse-to-patient ratio in an emergency department is 1:4 or fewer (Driscoll et al., 2018). Acute nursing shortage (a nurse: baby ratios of 1:15) as well as poor neonatal outcomes within neonatal units of public hospitals have been reported by recent studies (Murphy et al., 2016).

The observational data and discharge interview data allowed me to identify the tasks that the mothers were involved in. As presented in Chapter 6, mothers in this study were involved in tasks such as bathing/top tailing, feeding, KMC, and observations. The key differences between the two study hospitals were in the timing and the support received. While in Kijani, mothers took on tasks soon after admission with minimal formal support from the nurses. In Tausi their involvement in tasks started after 24 hours and with much more formal support from the nurses. This compares with a national survey conducted in Europe by the Picker Institute which also noted that 75% of the respondents reported having received formal support with tasks such as feeding and expressing milk. Respondents taking part in this survey appreciated having been involved in the care of their babies; (81% of the participants

reported involvement in the day-to-day care of their baby, over 76% mentioned having been encouraged to touch, hold and comfort their baby, only half were satisfied with the amount of KMC/skin to skin contact with their baby) (Howell & Graham, 2011).

Analysis of the narrative interview data brought to light the experiences of these mothers. As reported by several other studies, mothers of premature babies often experienced shock, anxiety, and fear (Cervantes et al., 2011; Ncube et al., 2016; Veronez et al., 2017). In light of all these traumatizing experiences, my study has also revealed key coping strategies of the mothers, which have also been identified elsewhere (Cervantes et al., 2011; Delgado Galeano & Villamizar Carvajal, 2016). These included supportive relationships from nurses, family, and other mothers, detachment, and faith (Chapter 7). Despite the myriad of challenges observed in the public hospital, an interesting finding following the analysis of the observations, interview and narrative data from my study, was that mothers in the public hospital had no more complaints and were equally appreciative of the care their babies received despite the glaring inequities and quality gaps.

### 8.2.1 Revised conceptual framework.

At the start of the study, I developed a conceptual framework in order to steer the research. It guided the choice of methods and data collection process. This initial framework showed that contextual, as well as health systems factors, could probably have an impact on the experiences and roles of mothers of hospitalised sick newborns. Based on my findings, I have made some modifications to the framework to illustrate how the four principles of FCC are differentially affected by underlying social, cultural, economic, and health system factors. The revised conceptual framework (figure 8.1), illustrates that in my study context two of the principles of FCC care provision (information and collaboration) are directly influenced by the underlying philosophy (the formal norms) of biomedical care in both hospitals. However, this dominant paradigm of care is moderated in practice by the functional capacity of the hospital affecting the third principal of FCC, participation. This difference in functional capacity results in different practical norms of care with perhaps paradoxical differences in levels and type of participation by mothers in the care of their baby – greater participation (better alignment with the principals of FCC) in the less well-resourced hospital. However, in terms of the fourth principle of FCC, the dignity and respect afforded to the mother, there is also a difference between the two hospitals with the difference directly related to the social, cultural and economic capital of the mothers where

mothers with the least social, cultural and economic capital were being given the least respect.

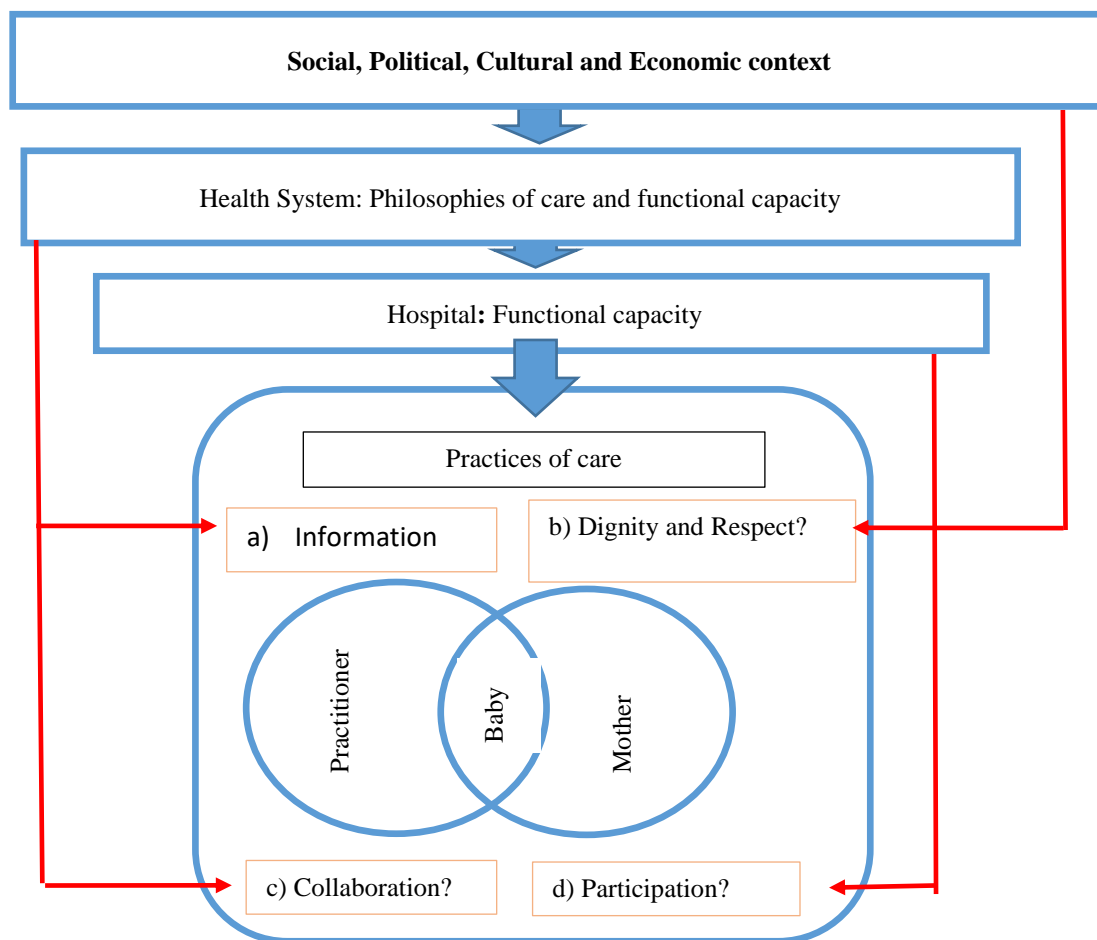


Figure 8. 1 Revised conceptual framework

### 8.3 Key observations in relation to the practices of care in the neonatal units.

In relation to my study's fourth specific objective, I now examine how care provision within the two study NBUs aligns with the core principles of FCC and the extent to which the FCC assumptions and conceptual framework are useful and feasible in the Kenyan context.

#### 8.3.1 Dignity & Respect

A core principle of FCC is that dignity and respect are accorded to the patient and their family. This focus on dignity and respectful care provision is echoed in the recent integration of respectful maternity care (RMC) into international and national maternity care guidelines

(WHO 2018). As described in chapter 2, dignity and respect in care provision require that service providers listen to, and honor, individual and family perspectives and choices taking into consideration their knowledge, values, beliefs and cultural backgrounds (Banerjee, Aloysius, Platonos, & Deierl, 2018; Kuo. et al., 2012). The mistreatment of women seeking antenatal care and delivery services in LMICs have been reported by several studies over recent years with forms of mistreatment reported including, physical and verbal abuse (Ratcliffe et al., 2016; Rominski et al., 2017; Sharma et al., 2019; Warren et al., 2017). However, to date, little attention has been paid to how mothers are treated in neonatal units in LMICs. The data from my study suggest that mothers in the public hospital, in particular, are also subjected to verbal abuse and disrespectful care.

Ishola and colleagues in their systematic review of disrespect and abuse of women during childbirth in Nigeria observed that mistreatment and abuse are linked to women's low socioeconomic status, low education, and a lack of empowerment (Ishola et al., 2017). These findings are similar to findings from other studies conducted in Pakistan, Malawi and Kenya (de Kok et al., 2020; Sheferaw et al., 2017) which also report disrespect and undignified care during ANC and maternity received by women of lower socioeconomic status. 97% of women who participated in a cross-sectional household-based study conducted in Tehsil Kharian of district Gujrat, India reported abuse and disrespect and this was particularly among the women of lower socioeconomic status who had delivered in a public hospital (Azhar, Oyebode, & Masud, 2018). A recent publication from a qualitative study conducted in Kilifi and Kisii counties in Kenya gathered views on disrespectful care during pregnancy, labour and delivery through FGDs with women and community health committee members as well as through key informant interviews with key stakeholders made similar observations (Lusambili et al., 2020). This relationship between a mothers' social and economic background and the manner in which she is treated resonates with the findings in my study, suggesting that these behaviours are not confined to antenatal care and the maternity ward but are reproduced within neonatal units. The mothers of Kijani were treated with much less dignity and respect than mothers with higher social and economic capital in Tausi.

For example, as described in chapter 5, disrespectful and undignified care in Kijani was manifested in the handling of the dead babies who were left lying in one section within the ward adding to the fear of death and anxiety for the mothers. The undignified nature of the care provided to the poorer women of Kijani is further illustrated by the failure to maintain high standards of cleanliness of the ward as well as through the observed nature of the relationships between the nurses and the women. The asymmetrical relationships in Kijani

is evidenced by differentiation in the shoe racks and chairs for the mothers and staff. Further, my study has shown how these Kijani mothers had to earn the respect of the nurses through complying with the stipulated norms and regulations in order to be treated well. Those who failed to fit into the role of the ‘good mothers’ were then further isolated by the staff as well as other mothers, making things quite difficult in the end. Disrespect for the ‘bad mothers’ who were most likely the most vulnerable due to their social status, was evident in the way such mothers were addressed. The most vulnerable in this case were the younger first-time mothers and those who lacked stable forms of social support systems and networks. They were scolded for failing to comply with the norms. Some of these mothers were also the ones who were detached from their babies, which my findings in chapters 6 and 7 indicate is a form of coping mechanism amongst some of these mothers in the light of the uncertainty of the outcome of their babies.

This inequity in the respectful treatment of the mothers in the two hospitals reflects the status of poorer people in the community more broadly. The benign neglect of the poor in the community and the influence of broader social and economic constraints on health outcomes of the underprivileged due to the structural violence they suffer is well documented in the works of many critical medical anthropologists (P. E. Farmer, Nizeye, Stulac, & Keshavjee, 2006; Gamlin & Holmes, 2018; Sadler et al., 2016). Nancy Scheper-hughes for example in discussing structural violence asserts that this form of violence “*naturalizes*” *poverty, sickness, hunger, and premature death, erasing their social and political origins so that they are taken for granted and no one is held accountable except the poor themselves*” (N. Scheper-Hughes, 2004). In her study conducted in the impoverished Northern Brazil, an area that was characterised by high infant mortalities, she highlights the impact that these high number of deaths had on the mothers. She observes that in such an environment many lived in economic hardships and women lacked any form of social support system. She concludes that these hardships within which the women lived in shaped how they perceived the weaker children. She postulates that such malnourished weaker children were considered better off dead and as such children died of neglect, which she traces back to the broader macro-level factors of poverty which the people in this community lived in.

Taking a structural violence lens into their study of mistreatment and abuse of women during the postpartum period in Tanzania, Miltenburg and colleagues argue that undignified care and mistreatment of women originate from the neglect to women’s lives by larger social, economic and political structures (Solnes Miltenburg, van Pelt, Meguid, & Sundby, 2018).



In this Tanzanian study, the participating women reported both supportive and non-supportive care, disrespect and abuse which ranged from verbal abuse, long waiting times, denial of services and not being provided with information. In parallel with the findings of my study, they observed that report of abuse and disrespect was higher amongst younger less experienced mothers, many of whom grew up in poverty and had far less social and economic capital. They noted that in Tanzania, many of these young girls dropped out of school, had higher rates of teenage pregnancy and were ultimately pushed into early marriages. These conditions, they further note compromises the financial independence of these young women in Tanzania, exposing them to disrespectful and undignified care. This study, therefore, draws our attention to the need to look beyond the proximal issue of the relationship between the provider and client and emphasizes the importance of examining disrespect and abuse as a systemic issue. The authors also point to the fact that the providers of care themselves are ‘victims’ of the system, that they have to cope with the challenges of understaffing and inadequate resources.

Similarly, my findings demonstrate the underlying benign neglect and structural violence in public sector hospitals in Kenya. While the two hospitals in my study are located within the same city and are only about 5 kms apart, my data point to the stark contrasts in the availability of resources between them. My observations add to the growing evidence of the appalling state of government-run facilities such as Kijani. As presented in chapter 5, the NBU ward of Kijani hospital was neglected in terms of human resources, medical supplies and structural repair. Unrepaired water tanks would overflow, and it was common for taps to run dry, there was inadequate supply of soap for washing hands, all of which have direct implications for the care quality. Nurses were overstretched and coped with the daily challenges of overcrowding and lack of supportive supervision. Just prior to the initiation of my fieldwork, and as part of the broader HSD-N study described in chapter 3 (Murphy et al., 2016), Kijani NBU was part of an ethnographic study looking into nurses’ collective strategies of coping with work-related stresses in Kenya (McKnight, Nzinga, Jepkosgei, & English, 2020). The study vividly describes how nurses work long hours, care for very many babies with minimal supportive supervision, and are simply unable to meet national and international standards of care leading to significant stress. Their findings indicate that these pressures shape the way nurses provide care and the strategies they employ to cope. Among others, these strategies include focusing on the clinical needs of the neonate and ‘routinizing care’ (focusing on the routine rather than the patient) – practices that run counter to the tenets of FCC and RMC (McKnight et al., 2020). In such resource-constrained and challenging settings, the concepts of FCC and RMC need to extend beyond the patient or the mother and

into consideration of the conditions under which the providers themselves are trying to ‘do their best’ in care provision. That is, the providers also deserve dignity and respect, demonstrated through the provision of a better working environment and a more supportive system.

Evidence that there is little political commitment to providing this support to the public sector hospitals in Kenya is shown by the major nurses and doctors strike that occurred during my data collection (see chapter 3) which resulted in the closure of the public hospitals across the country for extended periods. During the time of the strikes, there was a national election and yet the issue of the closure of public hospitals was largely ignored during the political debates. This is an example of just how those who work in and rely on the public sector are “ignored” by the politicians. These forms of neglect and structural violence emphasize that it is important to look at dignity and respect more broadly taking into consideration both the proximal as well as more distal systemic issues that may impact the way care is provided, in ante-natal care, maternity and neonatal units. As Kok and colleagues assert *“rather than blaming nurse-midwives for not upholding women’s right to respectful care, we should frame disrespectful care as a problem of fraught relationships and mutual distrust produced by a hierarchical context and disabling environment”* (de Kok et al., 2020).

In summary, my results suggest that the social, economic and cultural context of care is a key factor in the dignity and respect accorded to the mothers in the two neonatal units. The women in Kijani due to low social and economic status were treated with less dignity and respect than Tausi) – as shown by the data presented in chapters 5 & 6.

### 8.3.2 Participation

While the underlying paradigm in both hospitals is primarily biomedical, and directly influencing the sharing of information and collaboration on decision making, wider health systems factors also greatly influence the individual hospital’s functioning capacity. Kijani, the public hospital is managed directly by the Nairobi County government, while Tausi hospital is run independently by a church. Thus, the two hospitals have different management and funding streams. The availability of funding and resources directly affects the hospital’s functional capacity and ability to practice care in line with the biomedical formal norms of care provision. While the formal norms of care across the two hospitals and with hospitals in HICs are similar, there are noticeable differences in the implementation of these formal norms in practice. These differences are apparent in the level of participation

in care by the mothers and the supervision provided by the nurses. Data in Chapter 6 shows that of the two study hospitals, mothers in Kijani had to participate in more tasks, at an earlier point in their baby's hospitalisation and with less supervision because the hospital lacked the functional capacity to deliver care in line with the formal norms of care. This understaffing within public hospitals such as Kijani is also a form of structural violence. This structural violence paradoxically meant that Kijani mothers were more involved in care, and this was purely as a result of need (chapter 6). Involvement in care as a result of need as the case was in Kijani, negates the whole idea of FCC, of allowing mothers to choose when and to what extent they would wish to participate in care.

Studies from HICs presented in Chapter 2 illustrated the importance of parental involvement in the care of their hospitalised sick newborns. In HICs, studies have reported parental involvement in tasks such as nappy changing, feeding, comforting the newborn and KMC (Howell & Graham, 2011). Among the benefits of parental participation were reduced anxiety and stress in parents, increased satisfaction with care, and enhanced attachment and an increase in parenting confidence (Gooding et al., 2011; Herbst & Maree, 2006; Lee & O'Brien, 2014). My findings illustrate that indeed mothers in both hospitals were involved in caring for their hospitalised babies. In both settings, mothers were involved in feeding, bathing/top tailing, diaper change, and observations (keeping an eye on the baby and notifying the nurse in case they noticed a problem). However, this study has brought to light key differences (see table 8.1) which have direct implications to the mother's ability to effectively take on these roles as well as in the way in which these mothers are prepared and introduced to these tasks, especially in such emotionally challenging environments.

Additional insight into the potential effects of including mothers in the provision of care for their babies was that the mothers who became involved in care early in the process had the potential to develop greater agency within the NBU environment. Through participation and being a source of support for other mothers, my study found that these mothers, many of whom had very low economic and social capital, were eventually able to gain position and acquired more agency in caring for their baby and in negotiating the NBU environment. They were able to build on their agency as they acquired more social and cultural capital in relation to activities of the NBU. Such findings are an important addition to the discussions of concepts of power and agency in health care provision and provider/patient relationships in LMICs. Allowing mothers to actively participate in the care of their babies as and when they wish further contributes to dignified and respectful treatment of mothers within NBUs. Engaging them and providing the space and support for them to actively participate in certain

roles, allows them to feel part and parcel of the babies care and life. Data presented in chapter 6 from Tausi hospital highlighted how some of the mothers especially those whose babies were premature or whose babies were admitted to the critical care unit felt excluded from the care of their babies. In their narratives, these mothers talked about wanting to be involved in certain tasks and voiced their displeasure when at times they were asked to leave the room during tasks they considered simple such as feeding. As presented in chapters 6 and 7, care of the critical babies in Tausi was highly medicalised and mothers were aware of the relational dynamics and importance of maintaining these relationships with the nurses especially since, with early discharge, their babies remained under the care of these nurses. As such, this puts into question their autonomy with regards to the ability of mothers in such a highly medicalized environment to fully participate in care without disturbing the relationships with the nurses. Medicalization has been defined as *the process by which some aspects of human life come to be considered as medical problems and the application of the medical gaze to human conditions* (Illich, 2003). In my study, feeding and bathing of the premature babies in Tausi hospital which some of the mothers felt was not so sensitive was medicalised and done only by the nurses.

Research on neonatal health has led to the development and promotion of key maternally delivered interventions such as KMC (Conde-Agudelo & Diaz-Rossello, 2016; Smith, Bergelson, Constantian, Valsangkar, & Chan, 2017). KMC is praised for its benefits to both baby and mother. These benefits include; temperature and blood pressure regulation, heart rate, and respiratory stability, brain, cognitive and motor development, improved immune system function, weight gain, greater mother-baby bonding and decreased length of hospital stay (Chisenga, Chalanda, & Ngwale, 2015; Conde-Agudelo & Diaz-Rossello, 2016; Vesel et al., 2015). In addition, policies and care guidelines outlined in Chapter 3 also point to the importance of early skin to skin contact and breastfeeding. However, some of the observations made in my study point to issues that could potentially impact on the successful implementation and adoption of these strategies. As my study has shown, these gaps are hospital context-specific. For public hospitals such as Kijani, some of these gaps are structural and include financial support of KMC which could hinder its successful implementation. For Tausi hospital, on the other hand, it is the existing practical norms of care which initially lead to separation of mother and baby, the separation continued as mothers were also encouraged to go home following discharge from maternity having an impact on breastfeeding as well as the practice of KMC. There is also a growing interest in the area of disrespect of newborns and part of disrespect for the babies included being separated from their mothers which has been shown to negatively impact the emotional

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wellbeing and developmental outcomes of such babies (Sacks, 2017). My findings from chapter 6 illustrated how separation, as a result of the medicalization of care of the critically ill neonates introduced mixed feeding for the mothers of stable babies who are well enough to breastfeed.

### 8.3.3 Information sharing and collaboration

Despite the differences afforded in terms of dignity and respect and practical involvement, the information sharing and collaboration in care were equally poor in both hospitals irrespective of the social and economic capital of the mothers across the two study hospitals. Data presented in chapters 6 and 7 indicate that mothers in the two study hospitals were very much concerned by the lack of timely and adequate information. This lack of information contributed greatly to their fears and anxieties presented in chapter 7 of this thesis. The provision of timely and adequate information has been highlighted as key for discussions around dignity and respect. A descriptive qualitative study conducted in Turkey, for example, observed that the users of services as well as the service providers acknowledged the importance of effective communication to dignified care (Aydin Er, Incedere, & Ozturk, 2018).

This reported gap in communication and collaboration with mothers regarding care provision could potentially be linked the medicalization of care, which in my study was very prominent in Tausi and to the biomedical approach to care in both hospitals (R. Flacking et al., 2012; Thomson, Moran, Axelin, Dykes, & Flacking, 2013). The NICU environment is medicalized due to the technology that aids in the care of the very sick babies as well as the medical jargon used by the nurses and clinicians. Heermann and colleagues conducted a qualitative study in the US where they interviewed mothers of premature babies, their study report on the impact of such medicalized environments on mothering in NICU. In their qualitative study, interviewed mothers described the medicalized NICU environment as intimidating and overwhelming (Heermann, Wilson, & Wilhelm, 2005). This is similar to my findings where for instance some of the mothers felt scared by the machines and equipment such as the incubators and the phototherapy machines. In my study, some of the mothers did not fully understand the purpose of some of the machines as well as some of the information provided to them during ward rounds. A good example would be a lack of comprehension of what conditions such as jaundice is and the purpose of placing babies on phototherapy. I found that some of the mothers did not comprehend these fully leading to one of the main fears, the fear of the machines, which I describe in chapter 7. In line with current Kenyan policies, medical practice and care for sick newborns across both hospitals

is heavily influenced by the biomedical approach to care, with little mention of FCC and lack of clear direction on what can be done in terms of moving towards patient-centered/family-centered approaches to care in neonatal care (see Chapter 3). Data from previous studies have shown that hospital paradigms of care in many LMICs, and Kenya in particular, are fundamentally biomedical as also seen in HIC settings (Bruce & Ritchie, 1997; Jolley & Shields, 2009; Kuo. et al., 2012; Murphy et al., 2016). What this study has revealed is that this paradigm of care is influencing the enactment of two out of the four key tenets of FCC - specifically, i) information sharing, and ii) collaboration in both the study hospitals. Attitudes and practices around these two principles were very similar in both hospitals. Inadequate and untimely information sharing with the mothers and minimal levels of mothers' collaboration in the organization of care (as revealed by both the observation as well as the narrative data) delayed mother's participation in care in Tausi (see Chapters 6 and 7). Data from this study has also shown that fathers were minimally involved in the decisions and organization of care.

This lack of information sharing and collaboration is not unique to Nairobi, or Kenya and adds to the anxiety and stress experienced by the mothers. Just like many studies from HICs, this study observed that mothers of hospitalised sick newborns have many fears relating to the condition of their baby, medical procedures, the NBU environment, size of their baby as well as his/her outcomes (Aagaard, Uhrenfeldt, Spliid, & Fegran, 2015; Al Maghaireh, Abdullah, Chan, Piaw, & Al Kawafha, 2016; Burger et al., 2015; Cervantes et al., 2011; Fenwick et al., 2008; Fernandez Medina et al., 2018; Hall et al., 2013). The need to share information and develop collaborative decision making is important as a lack of communication has been shown to further intensify the fears and anxieties of mothers. This, in turn, has been shown to affect mother-baby bonding and attachment (I. T. Coyne, 1995; Enke, Oliva, Miedaner, Roth, & Woopen, 2017; R. Flacking, Thomson, & Axelin, 2016; Granero-Molina et al., 2019; Sargent, 2009). As highlighted in Chapter 2, studies in HICs have identified unmet needs which include i) a need for information (Herbst & Maree, 2006; Kowalski et al., 2006; Kuo et al., 2007; Wigert et al., 2013), and ii) a need for orientation and preparation (Herbst & Maree, 2006; Melnyk et al., 2008).

Since the needs and gaps identified by mothers in this study seem to be universal, understanding if and how HICs have dealt with these challenges and adapting some of the interventions to the local context could provide some key solutions for our setting. For example, some of the interventions that the literature review in chapter 2 found included: COPE which is a nine months educational-behaviour intervention in the US has been

developed to help parents of premature infants cope with the stress of premature delivery (Melnyk et al., 2008). Immediate short time solutions such as providing mothers with counseling support may be attainable in our setting provided that the staff are made aware and offered the necessary skills to do so.

#### 8.3.4 Implications for FCC, RMC and quality improvement strategies in LMICs

My study has reinforced the knowledge that public hospitals in Kenya are severely under-resourced and the findings illustrate that these gaps in resources have implications for the successful implementation of FCC and RMC in neonatal units in public hospitals. Studies from HICs have pointed to the importance of staffing and ward layout/context to FCC (Cho, Chin, Kim, & Hong, 2016; White, 2006; White, Smith, & Shepley, 2013) and my results confirm that poor staffing and ward layout are equally constraints to implementation in LMICs. While staffing and resources were better in Tausi and mothers were treated with more dignity and respect, mothers were still not involved in decision making and received little information about the status of their child. Recent evidence has shown that most neonates requiring 24/7 neonatal care in Nairobi are cared for by public hospitals (G. Murphy et al., 2018). There is thus a need for improving and addressing some of the structural and health system gaps which have direct implications to the care quality that is available and accessible to the majority in the population. Crowding and low staff levels, the two most pressing needs, have been shown to have implications for the quality of care and outcomes for these already vulnerable babies especially in terms of infection prevention control (Fischer et al., 2019; Haley, 1982).

A comparison of the data collected from the two hospitals has brought to light some inequities as well as relational issues of importance to both FCC and RMC which are context-specific. My study, as well as other researches, have pointed to the implications of women's social class on relationships, communication as well as the kind of care available and accessed by the different groups, women of lower social-economic statuses are highly likely to get undignified and disrespectful care. As researchers point out, successful implementation of interventions such as FCC and RMC may be complicated by the highly heterogeneous contexts and may not be fully enforced (Thomson, Moran, Axelin, Dykes, & Flacking, 2013).

#### **8.4 Study strengths and limitations**

In this exploratory qualitative study, I was able to describe the roles and experiences of mothers whose babies were hospitalised in two hospitals in Nairobi. I had initially planned to conduct this study in public hospitals, however, the prolonged health worker strike in Kenya (2017) necessitated the broadening of the study hospitals to include a mission hospital. An important insight which this final inclusion of a public and a mission hospital has added to this study is that it provided me with an opportunity to have a comparative view of the practices of care and in-depth exploration of the observed differences across differently funded healthcare facilities, something which would not have been possible had I only concentrated on public hospitals.

Secondly, in this study, I applied an ethnographic approach to data collection using multiple methods. As I discussed in chapter 4, my positionality and own professional experience were important in the conduct of this study. Despite not being a mother, my past experience of having over 5 years' experience of conducting ethnographic research in Kenya, which previously involved research in antenatal clinics and maternity wards in Kilifi was important to the conduct of this study. This study allowed for the collection of data from my own personal observations as well as from the voices of the mothers through in-depth interviews at discharge and narratives collected post-discharge. Using these multiple methods allowed for the collection of different sets of data and comparison of the findings which has triangulated the findings.

Thirdly, in examining these issues, I applied theories of critical medical anthropology in the interpretation of the data which strengthens the theoretical analysis and adds to the replicability and generalizability of these findings. In comparing and contrasting the structure and organization of care between the two study hospitals, this study has further shed light on how wider contextual and health systems factors impact on the practices of care.

An additional strength of this study is that the design allowed for the collection of both prospectively and retrospective data. Observation data were collected during the hospitalisation of the baby; this has strengths in that the data collected was real-time reflecting the actual lived experiences of the mothers without having to reflect back, which at times is prone to recall biases. The discharge interviews were conducted at the point of discharge and this made it easy to follow up on some of the issues that were observed in real-



time. Narrative interviews, on the other hand, provided an unstructured way of collecting the mothers' stories without following a predefined question guide. Having this open way of storytelling allowed the mothers to tell their own stories in their own way, bringing out what was important to them. Conducting the narrative interviews at home also provided a different environment where the mothers could tell their own stories in the comfort and privacy of their homes away from the hospital environment.

In this descriptive qualitative study, I applied three methods to data collection, described in chapter 4. These were; Nonparticipant observations, in-depth interviews and narrative interviews. Non-participant observation provided vital information relating to the context of care, practical norms of the NBU, roles and nature of relationships in the NBU. The discharge interviews enabled me to follow up on and confirm some of the issues I had observed pertaining to the norms of care and the roles that mothers played in the NBU. Narrative interviews opened up the space for the mothers to talk about their journeys from pregnancy to post-discharge. Some of the important data elicited through the narratives were mothers' experiences with antenatal care, delivery services and as well as their worries and post-discharge.

With regards to the limitations, this study did not collect the views of the service providers relating to the roles of mothers and their views on the involvement and participation of mothers in NBUs. However, this study was embedded within a broader research project (HSDN that delivers for newborns) (Murphy et al., 2016) which was looking at coverage, structural factors, staffing levels and nurses' views on the quality of care. I was able to provide feedback on my emerging findings at various HSDN study meetings which brought together different researchers working on the various arms of the wider project, stakeholders who included frontline service providers and policy and regulatory level stakeholders. Providing preliminary feedback from my work in these meetings as well as the regular reflective meetings with the HSDN social science team opened forums for discussing some of the observations. These fora, in conjunction with regular meetings with my supervisors, provided great input in terms of directing the research process as a whole.

One main gap highlighted in the literature on experiences of parents of hospitalised sick newborns is the absence of the male voice. This study was not able to contribute substantially to filling in this gap as I did not interview or collect the views of the fathers of these babies. However, I did observe the father's presence on the NBUs and the support they offered to the mothers was prominent in the narratives of the mothers in both hospitals. This data

contributes to our understanding of broader social and economic constraints facing families particularly those from the lower social class in terms of the ability of these fathers to support their wives during the hospitalization of their newborns as they also provide and care for their families at home. Additionally, in this study, I excluded mothers whose babies died. It is likely that interviewing fathers and these women, especially in the public hospital, could have led to additional themes relating to the quality of care and outcomes being expressed.

## **8.5 Recommendations**

In light of the key findings from this study, in this section, I present my thoughts on possible ways to improve the experiences of mothers of hospitalised sick newborns and neonatal care in LMICs such as Kenya. I also provide some academic recommendations.

Immediate recommendations include:

- The presence of dead babies on the ward was upsetting for the mothers. It is therefore important to develop improved procedures for the handling of dead babies on the wards.
- Mothers drew a lot of social and emotional support from fellow mothers on the ward. It is therefore important to explore the potential for tapping into and strengthening the informal support mechanisms such as the peer support networks amongst mothers within NBUs.
- The medicalization of care in Tausi led to the delay in participation in care as well as the separation of mother and baby. In well-resourced facilities such as Tausi, it is important to develop systematic approaches to encourage mothers to participate in the care of their newborns. This would help minimize the feelings of helplessness and strengthen their efficacy and confidence in caring for their babies both during admission as well as post-discharge.
- Providing adequate support to mothers with tasks such as feeding and bathing in public hospitals such as Tausi. This would help minimize anxieties experienced by mothers especially in the critical phase of admission.
- The development of an orientation strategy of mothers around the time of admission and counseling into what the NBU is like, roles and expectations, this could happen within the first 24 hours of admission and could be supported by peers.

Medium-term and long-term actions would include:

- Advocacy at the national and international levels for the incorporation of a rights-based approach to care that promotes dignity and respect in neonatal care, where the rights of the mothers and the staff are taken into account.
- The development and roll-out of communications interventions targeting nurses that are aimed at encouraging empathic care, improving their communication skills as well as sensitizing them about the need and importance of providing psychosocial support to the mothers. One such intervention is the communications intervention that is currently being implemented with some of the nurses working in NBUs across hospitals in Kenya. This will be rolled out and evaluated in 2020.
- Hospitals could review their rotation of nursing professionals and having more nurses who are specific to the NBU.
- Improvement of NBU infrastructure within public hospitals. This is an important step towards attaining better working conditions for the nurses as well as the availability of consumables.
- Involving parents and healthcare providers who work in the NBU in codesigning research has the potential to lead to the development of interventions that enhance and support parental participation.

## **8.6 Areas for further research**

Areas for further research suggested by this study include:

- An investigation of disrespect of hospitalised sick newborns and their families in LMICs.
- An investigation of how cultural norms in the community and how these relate to class could potentially influence mothers' participation and experiences both within and outside the hospital.
- Exploration of experiences of mothers whose babies don't survive (those whose babies die while in the NBU as well as those whose babies die post-discharge).
- An investigation of the care-seeking pathways post-discharge for babies who were hospitalised immediately at birth.
- Since developing partnerships between mothers and nurses within the NBU emerged as important in the NBU, there is an opportunity to investigate how these can be developed and sustained over time across the different health sectors and contexts.
- An examination of key stakeholders' views on the inclusion of mothers in policy decision making arenas or as active members of quality improvement unit-based task forces or involving mothers and even their families in co-design intervention and strategies for quality improvement.

- An examination of the experiences of fathers of hospitalised sick newborns and the impact of newborn hospitalization on catastrophic expenditure on households and impact on the households more widely.

## **8.7 Conclusion**

This exploratory qualitative research study on the roles and experiences of mothers of hospitalised sick newborns has shown that mothers in NBUs in Nairobi take an active part in caring for their hospitalised sick newborns. This study has also shown that, in the Kenyan context as in others, premature delivery and hospitalisation of a baby is a stressful experience for mothers. Findings show the fears and stress these mothers undergo are related to the baby's condition, mothering under stressful and emotionally charged environments, NBU environment and medical procedures that their babies undergo. The mothers in this study thus experienced negative psychological effects and an interrupted bonding and attachment process with their babies. The long hospitalisation of their babies resulted in added additional tensions as a result of their disrupted lives at home.

Through an examination of the context and processes of care across the two study hospitals, this study has brought to light inequities in sick newborn care in Nairobi. This study adds to the debates around the provision of dignified and respectful care. Further, the application of a structural violence lens in the analysis draws our attention to the importance of analysing the implication of broader socio, economic and political factors to the quality of care and mothers' experiences.

This study is a first step towards documenting experiences of NBU mothers in Kenya. My findings are therefore a crucial first step for developing quality improvement strategies in NBUs in Kenya and will have relevance to other LMICs. These findings should inform discussions and policy efforts that will facilitate the development of strategies and programmes that are sensitive to the needs of mothers. The hope is that these interventions will support such mothers in facing this challenging situation and reduce the stress and long-term impacts of these experiences.

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## **Appendixes.**

### **Appendix A: Non-participant observation guide**

This study will involve spending extended periods of time within newborn units. This ethnographic approach will allow for the collection of thick descriptions of daily interactions and day to day activities of the newborn unit. Observations will focus on the roles of mothers in care provision, communication and interaction between the formal and informal caregivers, informal discussions/conversations with the participants in the newborn unit to elicit their perceptions and coping mechanisms. Non-participant observation will be employed during the pilot and the three to four months of formal data collection period within each facility.

- The story of the hospital stay.
- Daily routines; what role do mothers play? When and why do they perform these roles? How are they prepared to conduct these tasks/roles? Experiences with taking care of the sick newborn; challenges and what makes it easy for them to perform these roles. Mother newborn interaction during admission.
- Interaction between the nurses and mothers: When and how do they interact? What type of issues arise and how are they dealt with? How are mothers helped to cope with experienced challenges and stresses and by who?
- Decision making: How are mothers engaged in the care process and is there space for discussing the course of treatment with the nursing/clinical team. Are there discussions about the progress of the newborn?
- Perceptions of involvement in care.
- Key actors and their roles: Who are they and their roles?

## **Appendix B: In-depth interview guide**

- **Story of the admission/hospital stay**

- Please describe what happened immediately after birth and events that led to the admission?
- How can you describe what happened on the day of admission? Who received you at the NBU what happened?
- Please describe the fears and concerns that you might have had during admission.
- How long was the hospital stay?

- **My role**

- Please describe to me what happened on a day to day basis during the admission period.
- Can you list the tasks which you were involved in?
- In what ways did the nurse/clinical staff prepare you for these tasks? Who else prepared you for these tasks?
- How would you describe your level of competency and knowledge in performing the required tasks?
- What was your experience with caring for your newborn/ performing the tasks required of you?
- In what other ways would you have wished to be involved during the admission of your newborn?

- **Story of post-discharge**

- How would you describe your experience with caring for your newborn post-discharge?
- How is the baby doing and how are you able to care for your newborn post-discharge? Any concerns post-discharge?
- Please tell me how things have been since the baby was discharged (Probe for bonding, experience with caring for the newborn on their own).

## **Appendix C: Narrative interview Guide.**

### **Pregnancy and during admission.**

- What do you remember about your pregnancy?
- Can you tell me about the birth of your baby? What do you remember about how your baby was when she/he was born?
- Can you tell me about your typical day during your stay in the nursery?
- Tell me about how you used to find out what was going on with your baby?
- what were the best things about the care that you received?
- what were the things that you found the most challenging and upsetting?
- what kinds of support did you have during this time?
- while your baby was sick in the hospital, how involved were you in your life back home?
- what happened when you were finally discharged and came home?
- Having gone through this experience, would you say it helped knowing other mothers who were going through similar things?

### **Story of post-discharge**

- How would you describe your experience with caring for your newborn post-discharge, (Transition to motherhood)
- Tell me about your mothering experience during the time your baby was in the NBU. According to your experience, what factors have had the most influence on your adaptation to the role of motherhood, positively or negatively? Follow-up questions continued on the mothers' responses.
- How is the baby doing and how are you able to care for your newborn post-discharge? Any concerns post-discharge?
- Please tell me how things have been since the baby was discharged (Probe for bonding, experience with caring for the newborn on their own).
- Community and family support.



## Appendix D: Mothers consent form (Discharge interviews)

### KEMRI Wellcome Trust Research Programme: Mothers Information and Consent Form

#### *EXPERIENCES ROLES AND PERCEPTIONS OF MOTHERS OF HOSPITALIZED SICK NEWBORNS STUDY*

<b>Institution</b>	<b>Investigators</b>
KEMRI-Wellcome Trust Research Programme	Ms. Dorothy Oluoch, Prof. Grace Irimu, Dr. Caroline Jones, Prof. Mike English
Oxford Health Experiences Institute	Dr. Lisa Hinton

#### **Who is carrying out this study?**

This study is being carried out by KEMRI in collaboration with the Ministry of Health. KEMRI is a government organisation that carries out medical research to find better ways of preventing and treating illnesses in the future for everybody's benefit. Sometimes research involves only asking questions of patients, their parents, community members or health providers about what they know, feel or do. All research at KEMRI has to be approved before it begins by several national committees who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

#### **What is this study about?**

We are interested in documenting the roles and perceptions of mothers of hospitalized sick newborns. We aim to investigate how these experiences and their voices could be formally engaged in care provision strategies. We are also interested in learning how mothers cope with the stresses of caring for a sick newborn. We will be doing this using observations in newborn units, interviews with mothers of hospitalized sick newborns and use of audio/written diaries. The study will be taking place in Nairobi County. As a parent of a newborn admitted/who has been admitted in the newborn unit of one of the participating health facilities, we ask you to participate in the study.

#### **What will it involve for me/my child?**

If you agree to participate in this research; At discharge or during your review visit post-discharge, you will be requested for a more formal interview to talk about your experiences and your perceptions This interview will be conducted outside the newborn unit and will be

audio recorded with your permission to assist later in fully writing up the information. This interview will take about 30-50 minutes of your time.

**Are there any risks or disadvantages to me taking part?**

The risks involved are minimal. The main disadvantage is the time you will spend talking to us during the study. We will make sure that this time is convenient to you. You are also free to mention when you feel uncomfortable with the researcher's presence. In addition, you may feel uncomfortable discussing sensitive issues or having certain occurrences observed. You are free not to answer any question you feel uncomfortable with.

**Are there any advantages to me taking part?**

There are no personal benefits to taking part, but your responses will contribute to knowledge that may help to improve the quality of care for hospitalized sick newborns in the newborn units in hospitals in Kenya. When we schedule a study specific appointment for your discharge interview, we will reimburse your transport costs.

**What happens if I refuse to participate?**

All participation in research is voluntary. You are free to decide if you want to take part. If you do agree you can change your mind at any time and withdraw from the research. This will not affect you/your child's care now or in the future.

**Who will have access to information about me/my child in this research?**

All our research records are stored securely in locked cabinets and password-protected computers. Only a few people who are closely concerned with the research will be able to view information from participants. All digital recordings will be deleted at the end of the study and the SERU (Scientific and Ethics Review unit) will be notified of the deletion.

**Who has allowed this research to take place?**

All research at KEMRI has to be approved before it begins by several national committees who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

**What if I have any questions?**

You are free to ask me or any of our staff any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

[Ms. Dorothy Oluoch, KEMRI Wellcome Trust Research Programme, P.O. Box. 43640-00100, Nairobi. Telephone: 0716 336479

**If you want to ask someone independent anything about this research, please contact:**

Community Liaison Manager, KEMRI Wellcome Trust Research Programme, P.O. Box 230, Kilifi. Telephone: 041 7522 063, Mobile 0723 342 780 or 0705 154 386

*And*

The Secretary - KEMRI/Scientific and Ethics Review Unit, P. O. BOX 54840-00200, Nairobi, Tel number: 020 272 2541 **Mobile:** 0722 205 901 or 0733 400 003 email seru@kemri.org

**KEMRI Wellcome Trust Research Programme consent form for  
[EXPERIENCES ROLES AND OF MOTHERS OF HOSPITALIZED SICK  
NEWBORNS STUDY]**

I have had the study explained to me. I have understood all that has been read/explained and had my questions answered satisfactorily.

Yes (please tick) I agree to participate in discharge interview.

Yes (please tick) I agree for the interview to be audio-recorded

I understand that I can change my mind at any stage and it will not affect the benefits due to me/my child.

**Signature:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Participant name:** \_\_\_\_\_ **Time** \_\_\_\_\_

(Please print name)

-----  
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***Where parent cannot read, ensure a witness\* observes consent process and signs below:***

I \*attest that the information concerning this research was accurately explained to and apparently understood by the participant/parent/guardian and that informed consent was freely given by the parent/guardian.

**Witness' signature:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Witness' name:** \_\_\_\_\_ **Time** \_\_\_\_\_

(Please print name)

\*A witness is a person who is independent from the trial or a member of staff who was not involved in gaining the consent.

Thumbprint of the parent as named above if they cannot write:

-----

***[Following section is recommended, and in some cases, must be signed by person undertaking informed consent]***

I have followed the study SOP to obtain consent from the [participant/guardian]. S/he apparently understood the nature and the purpose of the study and consents to the participation [of the mother] in the study. S/he has been given the opportunity to ask questions which have been answered satisfactorily.

**Designee/investigator's signature:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Designee/investigator's name :** \_\_\_\_\_

Time \_\_\_\_\_

(Please print name)

**THE PARTICIPANT/PARENT/SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP**

## Appendix E: Mothers consent form (Discharge interviews and storytelling)

### KEMRI Wellcome Trust Research Programme: Mothers Information and Consent Form

#### *EXPERIENCES ROLES AND PERCEPTIONS OF MOTHERS OF HOSPITALIZED SICK NEWBORNS STUDY*

Institution	Investigators
KEMRI-Wellcome Trust Research Programme	Ms. Dorothy Oluoch, Prof. Grace Irimu, Dr. Caroline Jones, Prof. Mike English
Oxford Health Experiences Institute	Dr. Lisa Hinton

#### **Who is carrying out this study?**

This study is being carried out by KEMRI in collaboration with the Ministry of Health. KEMRI is a government organisation that carries out medical research to find better ways of preventing and treating illnesses in the future for everybody's benefit. Sometimes research involves only asking questions of patients, their parents, community members or health providers about what they know, feel or do. All research at KEMRI has to be approved before it begins by several national committees who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

#### **What is this study about?**

We are interested in documenting the roles and perceptions of mothers of hospitalized sick newborns. We aim to investigate how these experiences and their voices could be formally engaged into care provision strategies. We are also interested in learning how mothers cope with the stresses of caring for a sick newborn. We will be doing this using observations in newborn units, interviews with mothers of hospitalized sick newborns and use of audio/written diaries. The study will be taking place in Nairobi County.

As a parent of a newborn admitted/who has been admitted in the newborn unit of one of the participating health facilities, we ask you to participate in the study.

**What will it involve for me/my child?**

If you agree to participate in this research;

1. At discharge or during your review visit after your child is discharged from hospital, you will be requested for a more formal interview to talk about your experiences and your perceptions. This interview will be conducted outside the newborn unit and will be audio recorded with your permission to assist later in fully writing up the information. This interview will take about 30-50 minutes of your time.
2. After discharge, you may be requested to participate in storytelling exercise. This will involve audio recording of your experiences which with your permission will be shared with policy makers and nursing staff.

**Are there any risks or disadvantages to me taking part?**

The risks involved are minimal. The main disadvantage is the time you will spend talking to us during the study. We will make sure that this time is convenient to you. You are also free to mention when you feel uncomfortable with the researcher's presence. In addition, you may feel uncomfortable discussing sensitive issues or having certain occurrences observed. You are free not to answer any question you feel uncomfortable with.

**Are there any advantages to me taking part?**

There are no personal benefits to taking part, but your responses will contribute to knowledge that may help to improve the quality of care for hospitalized sick newborns in the newborn units in hospitals in Kenya. When we schedule a study specific appointment for your discharge interview, we will reimburse your transport costs. To compensate for your time, we will give you a small gift of a pack of diapers when we visit you at home.

**What happens if I refuse to participate?**

All participation in research is voluntary. You are free to decide if you want to take part. If you do agree you can change your mind at any time and withdraw from the research. This will not affect you/your child's care now or in the future.

**Who will have access to information about me/my child in this research?**

All our research records are stored securely in locked cabinets and password-protected computers. Only a few people who are closely concerned with the research will be able to view information from participants. All digital recordings will be deleted at the end of the study and the SERU (Scientific and Ethics Review Unit) will be notified of the deletion.

**Who has allowed this research to take place?**

All research at KEMRI has to be approved before it begins by several national committees who look carefully at planned work. They must agree that the research is important, relevant to Kenya and follows nationally and internationally agreed research guidelines. This includes ensuring that all participants' safety and rights are respected.

**What if I have any questions?**

You are free to ask me or any of our staff any question about this research. If you have any further questions about the study, you are free to contact the research team using the contacts below:

[Ms. Dorothy Oluoch, KEMRI Wellcome Trust Research Programme, P.O. Box. 43640-00100, Nairobi. Telephone: 0716336479

**If you want to ask someone independent anything about this research, please contact:**

Community Liaison Manager, KEMRI Wellcome Trust Research Programme, P.O. Box 230, Kilifi. Telephone: 041 7522 063, Mobile 0723 342 780 or 0705 154 386

***And***

The Secretary - KEMRI/Scientific and Ethics Review Unit, P. O. BOX 54840-00200, Nairobi, Tel number: 020 272 2541 **Mobile:** 0722 205 901 or 0733 400 003 email seru@kemri.org

**KEMRI Wellcome Trust Research Programme consent form for**

**[EXPERIENCES ROLES AND OF MOTHERS OF HOSPITALIZED SICK NEWBORNS STUDY]**

I have had the study explained to me. I have understood all that has been read/explained and had my questions answered satisfactorily.

Yes (please tick) I agree to participate in a post-discharge interview.

Yes (please tick) I agree for the interview to be audio-recorded

Yes (please tick) I agree to participate in the storytelling

I understand that I can change my mind at any stage and it will not affect the benefits due to me/my child.

**Signature:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Participant name:** \_\_\_\_\_ **Time** \_\_\_\_\_

(Please print name)

-----  
-----

***Where parent cannot read, ensure a witness\* observes consent process and signs below:***

I \*attest that the information concerning this research was accurately explained to and apparently understood by the participant/parent/guardian and that informed consent was freely given by the parent/guardian.

**Witness' signature:** \_\_\_\_\_ **Date** \_\_\_\_\_

**Witness' name:** \_\_\_\_\_ **Time** \_\_\_\_\_

(Please print name)

\*A witness is a person who is independent from the trial or a member of staff who was not involved in gaining the consent.

Thumbprint of the parent as named above if they cannot write:

-----

***[Following section is recommended, and in some cases, must be signed by person undertaking informed consent]***

I have followed the study SOP to obtain consent from the [participant/guardian]. S/he apparently understood the nature and the purpose of the study and consents to the participation [of the mother] in the study. S/he has been given the opportunity to ask questions which have been answered satisfactorily.



Designee/investigator's signature: \_\_\_\_\_ Date \_\_\_\_\_

Designee/investigator's name : \_\_\_\_\_

Time \_\_\_\_\_

(Please print name)

**THE PARTICIPANT/PARENT/SHOULD NOW BE GIVEN A SIGNED COPY TO  
KEEP**

## Appendix F: Approvals



# KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200, NAIROBI, Kenya  
Tel: (254) (020) 2722541, 2713349, 0722-205901, 0733-400003, Fax: (254) (020) 2720030  
E-mail: [director@kemri.org](mailto:director@kemri.org), [info@kemri.org](mailto:info@kemri.org), Website: [www.kemri.org](http://www.kemri.org)

**KEMRI/RES/7/3/1**

**December 08, 2016**

**TO: DOROTHY OLUOCH,  
PRINCIPAL INVESTIGATOR**

**THROUGH: DR. BENJAMIN TSOFA,  
THE DIRECTOR, CGMR-C,  
KILIFI**

Dear Madam,

**RE: PROTOCOL NO. KEMRI/SERU/CGMR-C/CSC056/3335 (RESUBMISSION 2 OF INITIAL SUBMISSION): EXPLORING THE EXPERIENCES PERCEPTIONS AND ROLES PLAYED BY MOTHERS IN CARING FOR THEIR IN-PATIENT SICK NEWBORNS; AN ETHNOGRAPHIC APPROACH**

Reference is made to your letter dated 24<sup>th</sup> November 2016. The KEMRI/SERU Secretariat acknowledges receipt of the revised application on 30<sup>th</sup> November 2016.


This is to inform you that the Committee determined that the issues raised at the 256<sup>th</sup> Committee A meeting of the KEMRI/Scientific and Ethics Review Unit (SERU) held on **September 13, 2016**, are adequately addressed.

Consequently, the study is granted approval for implementation effective this day, **8<sup>th</sup> December, 2016** for a period of one year. Please note that authorization to conduct this study will automatically expire on **December 07, 2017**. If you plan to continue data collection or analysis beyond this date, please submit an application for continuation approval to SERU by **26<sup>th</sup> October, 2017**.

You are required to submit any proposed changes to this study to the SERU for review and the changes should not be initiated until written approval from the SERU is received. Please note that any unanticipated problems resulting from the implementation of this study should be brought to the attention of SERU and you should advise SERU when the study is completed or discontinued.

You may continue with the study.

Yours faithfully,

  
FOR **DR. EVANS AMUKOYE,  
ACTING HEAD,  
KEMRI/SCIENTIFIC AND ETHICS REVIEW UNIT**

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In Search of Better Health



## KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200, NAIROBI, Kenya  
Tel: (254) (020) 2722541, 2713349, 0722-205901, 0733-400003, Fax: (254) (020) 2720030  
E-mail: director@kemri.org, info@kemri.org, Website. www.kemri.org

KEMRI/RES/7/3/1

December 15, 2017

TO: **DOROTHY OLUOCH,  
PRINCIPAL INVESTIGATOR.**

THROUGH: **THE DIRECTOR, CGMR-C,  
KILIFI.**

Dear Sir,

RE: **PROTOCOL NO. SERU 3335 (RESUBMITTED REQUEST FOR ANNUAL RENEWAL AND PROTOCOL DEVIATION): EXPLORING THE EXPERIENCES, PERCEPTIONS AND ROLES PLAYED BY MOTHERS IN CARING FOR THEIR IN-PATIENT SICK NEWBORNS: AN ETHNOGRAPHIC APPROACH.**

Reference is made to your letter dated December 11, 2017. The KEMRI SERU acknowledges receipt of your response to the issues raised during review of the annual renewal on December 15, 2017.

This is to inform you that the Committee determined that the issues raised by the expedited review team of the KEMRI Scientific and Ethics Review Unit are adequately addressed.

Consequently, the study is granted approval for continuation effective **December 15, 2017** for a period of **one (1) year**. Please note that authorization to conduct this study will automatically expire on **December 14, 2018**. If you plan to continue with data collection or analysis beyond this date, please submit an application for continuing approval to the SERU Secretariat by **November 02, 2018**.

You are required to submit any proposed changes to this protocol and other information pertinent to human participation in this study to SERU for review prior to initiation.

You may continue with the study.

Yours faithfully,

*for*  
  
**DR. MERCY KARIMI NJERU,  
ACTING HEAD,  
KEMRI/SCIENTIFIC AND ETHICS REVIEW UNIT**

---

In Search of Better Health



## KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200, NAIROBI, Kenya  
Tel:(254) (020) 2722541, 2713349, 0722-205901, 0733-400003, Fax: (254) (020) 2720030  
E-mail: director@kemri.org, info@kemri.org, Website.www.kemri.org

**KEMRI/RES/7/3/1**

**December 3, 2018**

**TO: DOROTHY OLUOCH,  
PRINCIPAL INVESTIGATOR,**

**THROUGH : THE DIRECTOR, CGMR-C,  
KILIFI.**

Dear Madam,

**RE: PROTOCOL NO. SERU 3335 (REQUEST FOR ANNUAL RENEWAL):  
EXPLORING THE EXPERIENCES, PERCEPTIONS AND ROLES PLAYED BY  
MOTHERS IN CARING FOR THEIR IN-PATIENT SICK NEWBORNS: AN  
ETHNOGRAPHIC APPROACH.**

*Forwarded: 7/12/18  
Mg...*

**DIRECTOR  
CENTRE FOR GEOGRAPHIC MEDICINE  
RESEARCH, COAST**

Thank you for the continuing review report for the period **December 15, 2017** to **October 31, 2018**.

This is to inform you that the Expedited Review Team of the KEMRI's Scientific and Ethics Review Unit (SERU) was of the informed opinion that the progress made during the reported period is satisfactory. The study has therefore been granted **approval**.

This approval is valid from **December 15, 2018** through to **December 14, 2019**. Please note that authorization to conduct this study will automatically expire on **December 14, 2019**. If you plan to continue with data collection or analysis beyond this date please submit an application for continuing approval to the SERU by **November 02, 2019**.

You are required to submit any amendments to this protocol and any other information pertinent to human participation in this study to the SERU for review prior to initiation.

You may continue with the study.

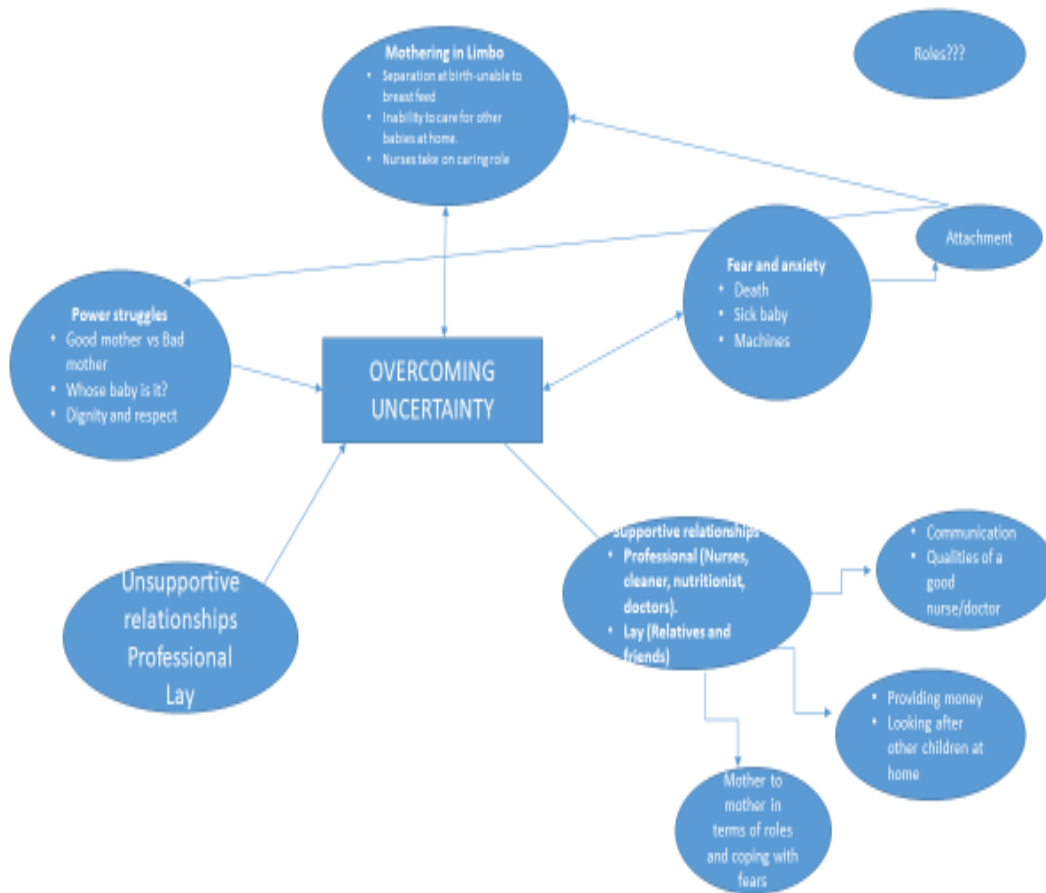
Yours faithfully,

**ENOCK KEBENEI,  
ACTING HEAD,  
KEMRI/SCIENTIFIC AND ETHICS REVIEW UNIT**



In Search of Better Health

## Appendix G: OSOP (One sheet of paper)



## Appendix H: Nvivo project codes

phd.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Go Refresh Open Properties Edit Paste Copy Merge Format Paragraph Styles Reset Settings Select

Workspace Item Clipboard

Look for: Search In Nodes Find Now Clear Adva

**Nodes**

- Nodes
- Relationships
- Node Matrices

**Nodes**

Name
Roles
Top tailing
Changing diapers
KMC
Phototherapy
Self efficacy
challenges
Feeding
Other
Relationships
Support systems
Fears and Concerns
Information sharing Decision making
Birth experience and perceptions of causations
Moments of transfer Babys progress
Nurses views of FCC
Stigma
community perceptions of preterm births
FCC

Sources

**Nodes**

Classifications

## Appendix I: Additional mothers' information

<b>KIJANI</b>			
<b>ID</b>	<b>mode of delivery</b>	<b>GA at delivery</b>	<b>Mothers report of complication at birth</b>
K01	SVD	Term	Baby ingested amniotic fluid and had difficulty breathing.
K02	SVD	7 months	Baby born prematurely.
K03	SVD	6 months	Baby born prematurely.
K04	SVD	7 months	Baby born prematurely
K05	SVD	7 months	Baby born prematurely
K06	SVD	Term	Baby had difficulty breathing
K07	SVD	8 months	Baby has difficulty breathing
K08	SVD	36 weeks	Baby had difficulty breathing
K09	CS	37 weeks	Baby had difficulty breathing and Jaundice
K10	SVD	Full	Baby had difficulty breathing
K11	SVD	8 months	Low birth weight
K12	SVD	7 months	Baby born before term
K13	SVD	Term	Respiratory distress
K14	SVD	8 months	Low birth weight
K15	SVD	7 months	Low birth weight
K16	CS	33 weeks	Low birth weight
K17	SVD	32 weeks	Baby born prematurely
K18	SVD	7 months	Baby born prematurely
K19	SVD	28 weeks	Twins born prematurely
K20	SVD	6 months	Baby born prematurely
<b>TAUSI</b>			
T01	SVD	term	Baby had difficulty breathing and jaundice
T02	SVD	term	Baby had difficulty breathing
T03	CS	term	Baby had difficulty breathing and infection.
T04	CS	term	Baby had difficulty breathing and an infection
T05	CS	37 weeks	Foetal distress
T06	SVD	term	Baby had Jaundice
T07	CS	term	Foetal distress
T08	SVD	term	Baby had Jaundice
T09	CS	term	Foetal distress
T10	CS	term	Baby had an infection
T11	CS	term	Baby had jaundice
T12	SVD	42 weeks	Baby had problems breathing
T13	SVD	term	Baby had jaundice
T14	CS	37 weeks	Cord prolapse baby had difficulty breathing
T15	SVD	term	Baby had jaundice
T16	CS	38 weeks	Baby had difficulty breathing
T17	CS	32 weeks	Baby born prematurely
T18	SVD	27 weeks	Baby born prematurely
19	CS	33 weeks	Baby born prematurely
20	CS	36 weeks	Twin pregnancy born prematurely