From the Department of Community Health and Behavioural Sciences,
Makerere University, Kampala, Uganda

and Department of Public Health Sciences,
Karolinska Institutet, Stockholm, Sweden

Seeking Referral Care for Newborns in Eastern Uganda: Community Health Workers' Role, Caretakers' Compliance and Provision of Care

Christine Nalwadda Kayemba

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To my beloved father, George Wilson Kayemba.
At your youthful age, you succumbed to the brutal regime at that time.
Rest in peace, Dad.

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THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

Christine Nalwadda Kayemba

Principal Supervisors:
Prof. Stefan Swartling Peterson
Karolinska Institutet
Department of Public Health Sciences

Assoc. Prof. David Guwatudde
Makerere University, College of Health
Sciences, School of Public Health
Dept. of Epidemiology and Biostatistics

Co-supervisor(s):
Prof. Göran Tomson
Karolinska Institutet,
Department of Public Health Sciences and
 Learning Informatics Management Ethics

Dr. Juliet Kiguli
Makerere University, College of Health
Sciences, School of Public Health
Dept. of Community Health and Behavioural
Sciences

Dr. Peter Waiswa
Makerere University, College of Health Sciences,
School of Public Health
Dept. of Health Policy, Planning and Management

Opponent:
Prof. Uwe Ewald
Uppsala University
Department of Women's and Children's Health

Examination Board:
Prof. Elisabeth Faxelid
Karolinska Institutet
Department of Public Health Sciences

Assoc. Prof. George Nasinyama
Makerere University, Directorate of Research and
Graduate Training

Assoc. Prof. Jerome Kabakyenga
Mbarara University of Science and Technology
Faculty of Medicine

ABSTRACT

Background: Newborn deaths contribute 44% of all under-five deaths. Community health worker (CHW) during home-visits may identify and refer newborns to health facilities for postnatal care and treatment of danger signs. However, little is known on the care seeking practices and health system capacity to care for healthy and sick newborns in sub Saharan Africa.

Objective: The overall objective of the studies was to assess newborn referral care seeking practices, compliance, and associated community and health systems factors in order to inform scale up of newborn care programs in Uganda and other low income countries with high newborn mortality.

Methods: Four studies (I-IV) nested within a cluster randomized trial were conducted between 2011 and 2013 at the Iganga-Mayuge Health Demographic Surveillance Site in eastern Uganda. In Study I, focus group discussions (n=12) with men and women and in-depth interviews (n=11) with mothers and traditional birth attendants were used to obtain a deeper understanding of the social and cultural factors that affect caretakers' compliance with community newborn referrals. Case vignettes, observations through role plays and record reviews were used in a cross sectional study to assess the ability of 57 trained community health workers to identify and refer sick newborns to health facilities (Study II). Study (III) was retrospective cohort of all referred newborns, during which interviews were held with 700 caretakers to determine compliance rate to seek health facility based care within 24-hours of a referral. In a cross sectional study, capacity to provide newborn care was assessed in all the 20 health facilities within the cluster randomized trial, using observations and interviews with of health workers (Study IV).

Results: Community members understood the newborn period differently from health workers. A seclusion period observed immediately after birth restricted movement of the mother and newborn until the umbilical cord dropped off, but was not binding in case of illness (Study I). Of the 57 CHWs assessed, 68% were considered knowledgeable with a median knowledge score of 100% (IQR 94%-100%), and 36 (63%) considered skilled in identifying sick newborns (Study II). A total of 724 newborns were referred, of which 700 were successfully traced. Fifty three percent (373/700) were referred for postnatal care/immunization and 47% because they had at least one danger sign (Study III). Overall, 63% of the caretakers of referred newborns complied within less than 24 hours, but more caretakers of sick newborns (243/327, 74%) complied, compared with 196/373 (53%) of those referred for immunization and postnatal care (p<0.001). A majority, (493, 77%) sought care from lower level health facilities. The determinants of compliance were: referred for danger signs Adjusted Odds Ratio (AOR) = 2.3, (95% CI: 1.6-3.5); CHW making a reminder visit to the referred newborn shortly after referral (AOR =1.7; 95% CI: 1.2 –2.7); and age of mother being 25-29 or 30-34 years, (AOR =0.4; 95% CI: 0.2 - 0.8) and (AOR = 0.4; 95% CI: 0.2 - 0.8) respectively; compared to the age group of less than 20 years (Study III). Fifteen of the 20 health facilities offered newborn care but level II facilities had the lowest availability score for resuscitation equipment (31%,) or newborn sepsis drugs (8%), and none offered kangaroo mother care. Two-thirds (33/50, 66%) of the health facility workers were considered knowledgeable in newborn care, but less than a half (17/42, 41%) skilled in newborn resuscitation (Study IV).

Conclusion: Trained community health workers when engaged in maternal-newborn programs can assist caretakers to recognize sick newborns, change long held norms like the 'seclusion'

and achieve good referral care seeking for newborns. There was high compliance with referrals, and caretakers mainly sought care from first level facilities which lacked capacity to care for sick newborns. Health workers had good knowledge about newborn care but unsatisfactory skills for resuscitation of newborns. Wherever deliveries are conducted there must also be health service readiness to care for newborn asphyxia and low-birth weight/prematurity. Policy and practice needs to change to enable lowest level health centres (HCII) to care for newborns with possible septicemia.

Key words: Newborn, community referrals, community health workers, compliance, health work knowledge and skills, capacity of health facilities

LIST OF PUBLICATIONS

I.   **Nalwadda CK,** Waiswa P, Guwatudde D, Kerber K, Peterson S, Kiguli J. "As long as the umbilical cord gets off, the child ceases to be called a newborn". Socio-Cultural beliefs and newborn referral in rural Uganda.(Submitted)

II.   **Nalwadda CK**, Guwatudde D, Waiswa P, Kiguli J, Namazzi G, Namutamba S, Tomson G, Peterson S. Community health workers - a resource for identification and referral of sick newborns in rural Uganda. Trop Med Int Health 2013 Jul 2;18(7):898-906. Epub 2013 Apr 2.

III.   **Nalwadda CK**, Waiswa P, Kiguli J, Namazzi G, Namutamba S, Tomson G, Peterson S, and Guwatudde D. High Compliance with Newborn Community-to-Facility Referral in Eastern Uganda: An Opportunity to Improve Newborn Survival. PLoS One, 2013;8(11): p. e81610.

IV.   **Nalwadda CK**, Tomson G, Guwatudde D, Kiguli J, Namugaya F, Namazzi G, Namutamba S, Nambuya H, Tagoola A, Peterson S, Waiswa P. Health system preparedness for newborn care: A health facility assessment in rural Uganda. (Submitted)

The papers will be referred to by their roman numerals I-IV.

CONTENTS

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AOD	Adjusted odds ratio
CHWs	Community Health Workers
cRCT	Cluster Randomized Controlled Trial
CI	Confidence Interval
DHS	Demographic Health Survey
GoU	Government of Uganda
ENAP	Every Newborn Action Plan
FGDs	Focus Group Discussion
HC	Health Centre
HIV	Human Immune Virus
HDSS	Health Demographic Surveillance Site
IDI	In depth Interviews
IMCI	Integrated Management of Childhood Illnesses
IQR	Interquartile range
KI	Key Informants
MDGs	Millennium Development Goals
MOH	Ministry of Health
NDP	National Development Plan
NHP	National Health Policy
OR	Odds ratio
PHP	Private Health Practitioners
PNFP	Private Not for Profit
SARA	Service Availability and Readiness Assessment
SSA	Sub-Saharan Africa
TBAs	Traditional Birth Attendants
TCMPs	Traditional and Complementary Medicine Practitioners
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic Survey
UN	United Nations
U5MR	Under-5 Child Mortality
UNEST	Uganda Newborn Study
UNICEF	United Nations Children's Fund
UNMHCP	Uganda National Minimum Health Care Package
USAID	United States Agency for International Development
VHT	Village Health Team

OPERATIONAL DEFINITIONS

Compliance: refers to a caretaker making a health facility visit within 24 hours following a community health worker's assessment of a newborn, and a referral made irrespective of whether care is received or not at the health facility

Delayed compliance: refers to a caretaker making a health facility visit after more than 24 hours

Healthy facility capacity: refers to the availability and interaction of health system inputs that should result into offering care to newborns, such as basic amenities, equipment, supplies, drugs, infection control, human resource, diagnostics policies and treatment guidelines.

Low birth weight: a baby born weighing less than 2500g. Low birth weight can be due to preterm birth, or can be full term but small for gestational age (Lawn et al. 2005; Lawn et al. 2013)

Neonatal mortality rate: number of deaths during the first 28 completed days of life per 1000 live births in a given year or period (Lawn et al. 2005)

Neonatal period: the first four weeks after birth (Lawn et al. 2005)

Newborn: a child under 28 days of age (WHO 2009)

Newborn danger signs: clinical signs in a newborn pointing to serious illness that can rapidly lead to death in the first weeks of life, such as: failure to breastfeeding, lethargy, convulsions, a cold body temperature (<35.5°c), hot body temperature (> 37.5° c), chest in-drawing, fast breathing (>60/ min), grunting, jaundice, reddening of the umbilical cord with pus, preterm and low birth weight (WHO 2009).

Newborn referral: refers to a process of taking a newborn from a household to a formal health facility for health care.

Noncompliance: refers to going to the health facility after more than 24 hours or not going at all.

Preterm: a baby born at less than 37 weeks of gestation (Lawn et al. 2010)

Stillbirth: all pregnancy losses after 28 weeks of gestation or when the fetus weighs 1000g (Lawn et al. 2010; Lawn et al. 2011).

PREAMBLE

It was a Monday morning in January 2010 when I made a courtesy call on my way to work to a friend and officemate, Rose*. She was expecting a baby and the day before had mentioned going to the hospital as she had passed 40 weeks of gestation. Her sister, Mary*, answered the phone, and told me that Rose was admitted to hospital and had started labour. She was in good general condition, though was not able to speak on the phone. Mary promised to keep me posted about my friend's condition. I shared the news of Rose's admission to hospital with my other officemates as they reported for duty. We were all anxiously awaiting the newborn.

An hour later, my phone rang. It was my friend calling. I hurriedly answered the phone, calling out her name and asking if she was through with "pushing". Alas!! She was sobbing; she could barely speak. Stammering, she said, "Christine... my baby is dead!" I screamed *banange (On my God)*!!! My colleagues inquired what was wrong. I held my mouth, gaped, and told them the unbelievable. They nearly fell off their seats, flooding me with questions about what had happened. I could not answer. My friend had only said that her baby was dead and hung up.

Two of us raced to the hospital where our friend had delivered. We rushed to the reception area and inquired for directions to the labour ward. As we set off, we noticed Rose's husband at a distance. He was dressed in a white shirt, red and black striped tie, and a black suit. He was pacing along the corridor of the labour ward, looking towards the ceiling. Our footsteps caught his attention, and he turned and our eyes met. Oh no, he was in tears! He led us to the room where our friend was admitted. There were two nurses in the room. One was wrapping the dead baby in a pink floral blanket as Mary looked on in tears, while the other nurse was closing the intravenous line that was running into Rose's hand. Rose's gray-haired father stood quietly in one corner of the room, with his head held up facing the wall, hiding his tears from us. Two other young women were leaning against the bed where our friend lay, with their hands crossed over their chests, gazing in the air. When Rose saw us, she struggled to sit up. She was weeping. We involuntarily fell victim to the tears; we hardly said a word. We just held her hands as tears freely rolled down our cheeks. I hate to recall the scene but I have to be brave and tell the entire story. She painfully recounted what had happened - how the baby had missed the 'golden minute'. The little girl had failed to breathe and died of asphyxia one of the three major causes of newborn deaths in Uganda and also worldwide. As Rose struggled to tell the story, an elderly male hospital worker knocked and opened the door. It was time to take away the body. Rose instantly stopped talking and covered her face with her trembling hands. She could not bear the sight, as her baby girl was silently wheeled away.

The long awaited baby, whom we had joked about, given names to, tickled as she stretched and wiggled in her mother's womb, was no more. No pink dresses or baby toys. Our anticipated happiness had faded instantly. We gloomily departed, our hearts torn into pieces. We drove in silence to a flower shop at Garden City, the closest shopping centre. The florist asked how she could assist us but our eyes told it all. Instead of a bright bouquet to congratulate Rose and her family, it was a wreath for their precious baby girl.

That afternoon we laid our beautiful Chantal to rest. She did not live to see her two brothers. I cannot keep my tears back as I type. In Uganda, every day one hundred and thirty four mothers

and their families go through a similar tragedy. Yet there are simple, cost effective, proven interventions that can prevent newborn deaths. As medical professionals, we knew this, but this knowledge did not prevent a tragedy befalling one of our own. I felt the gravity and reality of newborn mortality. It was at this point that I decided to join the researchers in my department and make a contribution towards promoting newborn health. I abandoned the HIV-related concept that I had finalized and started developing one around newborn health.

I am hopeful that this work will make a contribution towards saving the lives of newborns, in Uganda and beyond. The challenge is still enormous, but this hospital experience inspires me to continue working with newborn health even after this thesis.

*Mary and Rose not real names

1 INTRODUCTION

1.1 MATERNAL, NEWBORN, AND CHILD MORTALITY

A newborn is a child under 28 days of age, similarly, the newborn period is equivalent to the first 28 days life (WHO et al. 2009). While deaths of older children and mothers have been halved during the last two decades, newborn deaths and stillbirths have stagnated in the same period. The under-5 child mortality (U5MR) reduced from 90 deaths per 1000 live births in 1990 to 46 in 2013 (12.7 million deaths to 6.3 saving 17000 per day (UNICEF 2014a). The maternal mortality reduced from 380 deaths per 100,000 live births in 1990 to 210 in 2013 (Table 1) (WHO 2014a). Since 1990, the average annual reduction in newborn mortality rate (NMR) was 2.0% lower than that of children aged under five (3.0 %) and maternal mortality (2.6%) (UNICEF 2014a).The reduction for stillbirths was about 1%, with an estimated 2.6 million stillbirths every year, (Cousens et al. 2011; Lawn et al. 2011) with 45% happening during childbirth (Lawn et al. 2011). The reduction in U5MR is partly due to resources triggered by the efforts to realize the global framework, the Millennium Development Goals (MDGs), launched in the year 2000. The decline in U5MR is also attributed to cost effective, proven interventions such as immunization, insecticide-treated mosquitoes nets, rehydration salts, nutritional supplements and therapeutic foods (UNICEF 2014a). However, the U5MR reduction rate of 3.4% is lower than the set target of 4.4% per year (UNICEF 2014a) that is required to attain the fourth MDG. Unless the slow reduction in newborn mortality and stillbirths is hastened, this goal will not be realized (Lawn et al. 2014; WHO 2014b).

Table 1: Global maternal child and newborn indicators (1990-2013)

Indicator	1990	2013	% decline 1990-2013	Average annual reduction rate	MDG annual reduction rate target
*Maternal mortality ratio (Deaths per 100,000 live births)	380	210	45	2.6	5.5
§Under 5 mortality rate (Deaths per 1000 live births)	90	46	49	3.0	4.4
§Newborn mortality (Deaths per 1000 live births)	33	20	39	2.0	-

*Source: *WHO Trend in maternal mortality(WHO 2014a); §UNICEF Levels & trends in child mortality (UNICEF 2014a)*

1.2 GLOBAL NEWBORN MORTALITY

The neonatal period accounts for majority of deaths among children under-five, 36% in 1990 and 44% in 2012 (UNICEF et al. 2013a). This increase in the burden is due to the slow reduction in newborn mortality compared to that of the older children (1-59 months), and the trend will remain as the under-five mortality continues to decline (UNICEF 2014a). Importantly, there is a wide variation in the mortality and rate of reduction of newborn deaths between countries, regions and causes of death (Lawn et al. 2014). For example, the NMR ranges between 1 death per 1000 live births in Japan to 49.5 in Sierra Leone (Lawn et al. 2014). Also, from 2000 to 2011, eastern Asia has attained a reduction rate of 65% compared

to 28% in sub-Saharan Africa (SSA) (UNICEF et al. 2013a; Lawn et al. 2014). Whereas south Asia and SSA had the highest newborn mortality rates in 1990, (56 and 46 deaths /1000 live births respectively), they have had the slowest decline in the last two decades, of 39% and 32% respectively (UNICEF et al. 2013a; UNICEF 2014a).

Newborn deaths have been the biggest challenge to achieving MDG-4, of reducing child mortality levels of 1990 by two thirds by the year 2015. Unless necessary interventions are implemented, newborn deaths will remain a hurdle to attaining the new global targets set in the post-MDG era of reducing child mortality to 20 or fewer deaths per 1000 live births by 2035 (Lawn et al. 2014; UNICEF 2014b). Yet the majority of neonatal deaths are preventable (Darmstadt et al. 2005; Knippenberg et al. 2005; Martines et al. 2005) with proven, low cost, interventions, such as clean home delivery, hygienic cord care, thermal care, early and exclusive breastfeeding, and community-based care for low birth weight (Darmstadt et al., 2005). If made universally available, these interventions could reduce neonatal mortality by 60 to 90% (Darmstadt et al. 2005; Martines et al. 2005; Bhutta et al. 2014). Unfortunately, these interventions often do not reach those who need them most (Knippenberg et al. 2005; Martines et al. 2005) due to operational challenges in implementing them (Waiswa et al. 2008).

Factors contributing to high neonatal mortality include a high proportion of non-facility deliveries (Darmstadt et al. 2009b), poorly performing health systems (Lawn et al. 2009), detrimental newborn care practices (Waiswa et al. 2010) delay in seeking care, and poverty (Lawn et al. 2005). Inequities and sex differences have also been associated with neonatal mortality and these factors require further evaluation (Nielsen BB 1997), (Xu B 1997).

1.2.1 Global causes and distribution of newborn deaths

Causes of newborn deaths
Worldwide, 2.9 million newborns die from three main causes: complications from preterm births (35%), neonatal infections (28%), and complications during birth (Lawn et al. 2005; Black et al. 2010; Liu et al. 2012; UNICEF et al. 2013a) (Figure 1). However, between 2000 and 2012, there has been a change in some specific causes, with tetanus having the largest relative decrease of more than 60%, from 1.3 deaths per 1000 live births to 0.4 (Lawn et al. 2014). The decrease is attributed to the significant increase in immunisation against tetanus (Blencowe et al. 2010), and improved cleanliness at birth and cord care practices (Blencowe et al. 2011). Birth related complications decreased by about 30% (8.2 to 5.3 per 1000 live births)- partly due to increased institutional deliveries. Preterm deaths decreased by less than 20% and congenital causes by less than 10% (Lawn et al. 2014). However, extreme preterm increase neonatal morbidities (Austeng et al. 2010).

Over 80% of newborn deaths occur among low birth-weight babies, with two thirds among preterm and one third among full term but small for gestation age babies (Lawn et al. 2014). The majority of these deaths occur during the first seven days of life (Lawn et al. 2005; Alonso et al. 2006) and of these, about 60% take place in the first 24 hours (Malqvist et al. 2010; Lawn et al. 2012). Most often they occur at home (Lawn et al. 2005) making the first week of life the most vulnerable period in childhood. It is therefore crucial that all newborn babies access essential care within the first days of life (Darmstadt et al. 2005) to improve their survival.
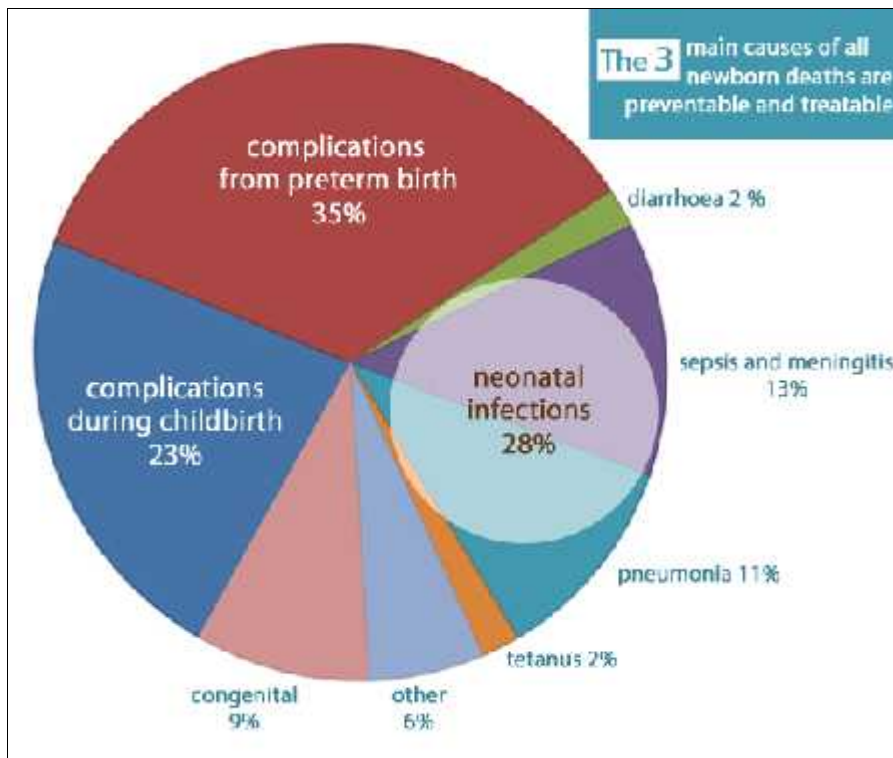
Figure 1: Causes of newborn deaths worldwide.
Source: Liu, L., H. L. Johnson, et al. (2012). "Global, regional, and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000." The Lancet 379(9832): 2151-2161.

Variation in causes of newborn deaths

Unlike preterm birth complications, which are leading causes of newborn deaths in low and high mortality countries (Liu et al. 2012), congenital abnormalities cause more newborn deaths in low mortality countries compared to high mortality settings (Modell et al. 2012). There is also a variation in cause of death between younger and older newborns. Whereas being preterm is responsible for 41% deaths in early newborn period (0-6 days), sepsis contributes to 37% of deaths in the late period (7 to 27 days) (Lawn et al. 2014). Sex of the baby is known to be a risk factor for newborn deaths, with male babies have a higher risk of dying during the newborn period than female babies, irrespective of their gestational age (Kent et al. 2012). Boys have increased risks of being born preterm (14%) (Zeitlin et al. 2002; Blencowe et al. 2013), suffering severe newborn infections (12%) (Seale et al. 2013) and suffering birth-related encephalopathy (42%) (Lee et al. 2013). However, in some settings, girls have an increased social risk of death (Lawn et al. 2014), following selective pregnancy termination, due to the preference of boys who are seen as propagators of family lineage, unlike the girls (Jha et al. 2011; Nie 2011).

Distribution of newborn deaths

More than 75% of all the newborn deaths occur in south Asia and SSA, which have the highest mortality rates (UNICEF 2012). Ten countries from these regions are responsible for 60% of all the newborn deaths worldwide (UNICEF et al. 2013a) (Figure 2). Notably, India and Nigeria together contribute to more than one million deaths out of the 2.9M that die every year

Countries with high newborn mortality - more than 40 deaths per 1000 live births - have been described as having at least one of the following: experienced conflict, high fertility rate, high

unmet need for family planning methods, high adolescent pregnancies and child marriages (Lawn et al. 2014).
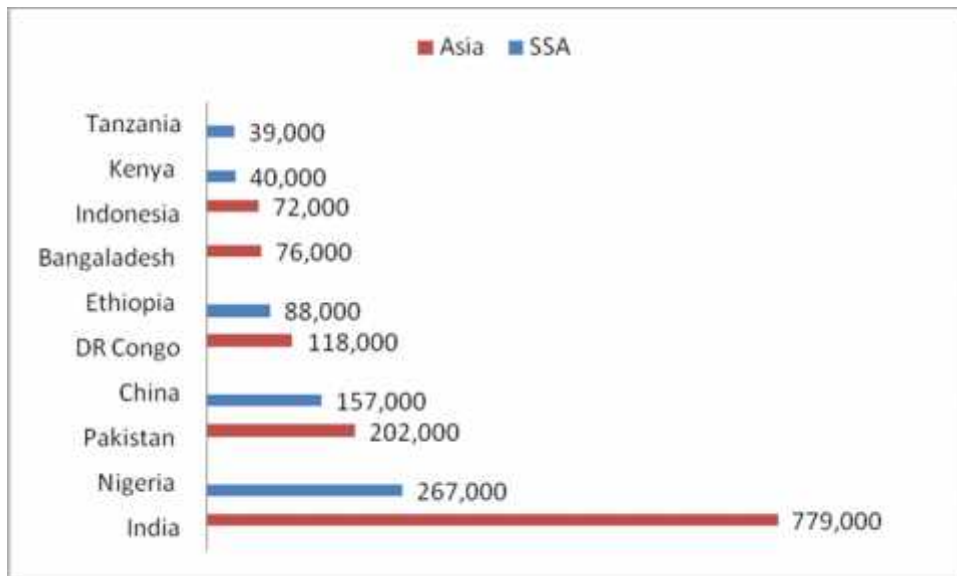
Figure 2: Top ten countries contributing to 60% of worldwide newborn deaths.
Source: Adapted from UNICEF, WHO, The world bank, UNFPA, 2013. Levels and Trends in Child mortality, report 2013

1.3 GLOBAL INITIATIVES TO ADDRESS MATERNAL NEWBORN AND CHILD HEALTH

1.3.1 Millennium Development Goals

In September 2000, a Millennium Declaration was endorsed by 189 countries and 147 heads of state at United Nations (UN) headquarters in New York City, New York, USA. From this declaration, eight MDGs were drafted to address eight major global problems by the year 2015 (United Nations 2000). In the past 13 years, nations have worked towards achieving these targets and in the process, have improved the lives of millions of people.

MDG 4 was meant to reduce the mortality rate by two thirds among children aged below five years (United Nations 2013), and so far, child mortality has almost halved: a 47% reduction from 90 child deaths per 1000 lives in 1990 to 48 in 2012 (UNICEF 2013b). However, no newborn targets were set (Mason et al. 2014) with limited funding towards newborn health (Pitt et al. 2012). Many countries in SSA may not achieve MDG 4, due to the slow decline in newborn deaths, which is the biggest contributor to under-five deaths. Furthermore, unless the current rate (3.4%) of reduction for child mortality is increased fourfold, the world will meet MGD 4 in 2028, 13 years after the set target (UNICEF 2013b). Using the same rates of decline, it will take over 100 years for an African newborn baby to attain the same survival probability as one born in 2013 in Europe or America (Lawn et al. 2014). Therefore, newborn and stillbirth goals and targets need to be incorporated in the post-2015 global plans to improve performance in newborn survival (Mason et al. 2014). There is also need to bridge the gap between the current health goals and post survival development outcomes of newborns (Lawn et al. 2014).

1.3.2 A Promise Renewed

 'A Promise Renewed' is a recent global initiative launched in 2012 by UNICEF and USAID to end preventable child deaths by 2035. It has already been endorsed by 179 countries. It brings together public, private and civil society actors committed to scaling up progress on maternal, newborn and child survival. Under this initiative, the target is to reduce under-five child mortality rates to less than 20 deaths per 1000 live births (UNICEF 2013b).

WHO and UNICEF coordinated and led a worldwide review process (WHO 2014) involving over 50 governments and hundreds of institutions and individuals to develop a global plan. The plan, Every Newborn Action Plan (ENAP), was endorsed at the 67th World Health Assembly, with the aim to stop preventable newborn deaths and stillbirths by 2035. It is based on the guiding principles of country leadership, human rights, integration, equity, accountability and innovation (WHO 2014b).

ENAP tasks all countries to strive for less than 10 newborn deaths per 1000 live births and less than 10 stillbirths per 1000 total births by 2035 (Lawn et al. 2014), in line with the child mortality target stated in 'A Promise Renewed'(UNICEF 2013b). The ENAP initiative will require all nations to invest in high-quality care before, during and after childbirth, for every pregnant woman and newborn. It also emphasizes the critical need for registration of all births and deaths. ENAP outlines an evidence-based framework towards care for every woman, a healthy beginning, and life for all newborns no matter where they are born (Mason et al. 2014). The plan also highlights what needs to be done differently, including leadership and more coordinated partnerships, parental voices, investment, implementation strategies, and indicators with effective data collection (Darmstadt et al. 2014).

1.4   EVIDENCE BASED INTERVENTIONS FOR NEWBORNS

1.4.1 Facility-based interventions for reducing newborn deaths

Health interventions essential to promoting maternal health are closely linked to those required to prevent the main causes of newborn deaths (UNICEF 2014a). Based on this concept, Bhutta et al., described a 'triple return on investment' whereby high coverage of existing proven interventions is estimated to save 3 million lives per year until 2025, including 162,000 women, 816,000 stillborn babies and 1.95 million newborns (Bhutta et al. 2014). The same authors categorize these interventions into four groups (Panel 1.)

> **I)** **Integrated antenatal care**
> **II)** **Quality of care at birth**
> - Skilled attendant at birth
> - Access to basic and comprehensive emergency obstetric care
> - Management of preterm labour
> - Appropriate use of antenatal corticosteroids
> **III)** **Essential newborn care**
> - Prompt resuscitation
> - Routine postnatal care for all women and babies
> **IV)** **Care of small and ill newborns**
>   Prevention and management of neonatal infections, kangaroo mother care and supportive care for preterm babies

Figure 3: Evidence-based newborn interventions.
Source: Mason, McDougall et al.. 2014.

Facility-based interventions at the time of birth (during labour, childbirth, and immediate postnatal care in the first week of life) have the potential to result in the greatest effect on mortality reduction for both babies and mothers (Bhutta et al. 2014). Prioritizing and offering quality care during this period is an opportunity to prevent maternal and newborn deaths and still births (Lawn et al. 2014; Mason et al. 2014). Countries that have had rapid progress towards a reduction in newborn mortality have also achieved a change in the fertility rate, the gross national income, implemented antipoverty programs and increased female literacy (Lawn et al. 2012; UNICEF et al. 2013a; Lawn et al. 2014). There is a global family planning initiative, FP2020 that was launched in 2012 that aims to reach 120 million users in the world's poorest countries by the year 2020 (Brown et al. 2014). Scaling up use of modern family planning methods, along with improved maternal and newborn care, is required to improve newborn survival.

1.4.2 Community health worker strategy to promote newborn survival Use of community health workers to identify and refer sick newborns

Kinney et al.et al.. reported that simple tasks can be shifted to community health workers, when there is a constraint with the number of health workers (Kinney MV 2010). A community health worker (CHW) has been defined as "a lay cadre, without formal health academic education, but given a range of trainings and usually recruited from within the community which they serve" (Byrne et al. 2014). A community health worker model in which they identify sick newborns, and make and facilitate referrals has been recommended (Winch et al. 2005) for linking the community and the health system in low income settings, and has been shown to improve newborn survival (Gogia et al. 2010).

Community empowerment and engagement has been recognized as playing an important role in the improvement of the general health of the respective population (Lewin et al. 2006). For instance, community based care characterized with curative services is estimated to avert about a quarter of newborn deaths, particularly in populations that cannot easily access services, such as those in rural or post conflict areas (Bhutta et al. 2014; Mason et al. 2014).

Also, community-based care, such as home visits by CHWs, (Martines et al. 2005), advancing the skills of CHWs (Pang et al. 2003), and health systems strengthening by CHWs facilitating referrals to bring sick newborns in contact with the health providers (Baqui et al. 2008; Darmstadt et al. 2010b), can reduce neonatal mortality in low income countries. Studies showed that home-based newborn care interventions can prevent 30 to 60% of newborn deaths in high mortality settings under controlled conditions (Bang et al. 1999; Baqui et al. 2008; Gogia et al. 2010; Darmstadt et al. 2010b). However, there is not yet available evidence to show the success of using CHWs to reduce newborn deaths in SSA,

Using the evidence from Asia, WHO and UNICEF recommend home visits in the baby's first week of life for the assessment of danger signs in the mother and newborn to improve newborn survival in communities with a poor health system, low healthcare use, and high neonatal mortality. In cases where danger signs are found, the family members are counseled to seek care immediately (WHO et al. 2009).

Due to contextual differences, there is a critical knowledge gap regarding CHW's accuracy in neonatal assessment at community level, particularly in the first week, when 75% of newborn deaths occur in SSA (Darmstadt et al. 2009a). One of the aims of this thesis was to contribute towards closing this knowledge gap by determining the CHWs' ability to identify newborn danger signs within a community trial, UNEST.

1.5 CULTURAL BELIEFS AND PRACTICES DURING NEWBORN PERIOD

In sub-Saharan Africa, little is known on the cultural beliefs and practices that may influence caretakers' compliance with referral care during the newborn period. Rather, there is more evidence on antenatal practices, birth preparedness, acceptability of the recommended newborn practices, and other newborn care practices (Bazzano et al. 2008; Waiswa et al. 2008; Kirkwood et al. 2013). In Bangladesh, Winch et al. reported that the newborn period was defined as the first 40 days of life compared to the 28 days by WHO. Furthermore, he found that the mother and the newborn are considered to be unclean, so they are isolated and restricted from moving outside the household, while people from outside the household are not allowed to visit the home (Winch et al. 2005). Mrisho et al., in Tanzania (Mrisho et al. 2008) and Dennis et al.et al.. (Dennis et al. 2007) also described a similar restriction for newly delivered mothers and their newborns. Such seclusion periods affect compliance to community referrals of newborns or general seeking care for the newborn (Kumar et al. 2009).

Decision making and gender issues in relation to newborn health are also not well understood in SSA. However, in Ghana, Bazzano et al., found that husbands, grandmothers and older women were key decision makers regarding a child's treatment needs (Bazzano et al. 2008). Victoria et al., also reported that in India, sex inequalities in health care seeking among children exist, where girls are taken to less qualified health practitioners and in the late stages of the illness, compared to the boys (Victora C G et al. 2003). Therefore, behavioral change strategies for promoting recommended newborn care need cultural and contextual adjustment (Karas et al. 2012).

In order to develop interventions to reduce newborn mortality, there is need to explore issues such as socio-cultural beliefs, the chronology of events during the neonatal period, newborn danger signs from the local perspective and how they are mitigated, the decision making

processes and gender issues in relation to newborn care seeking, and the role of traditional health practitioners like TBAs in newborn health care.

1.6   HEALTH SYSTEMS FOR NEWBORN SURVIVAL

1.6.1   WHO health system buildings blocks

"A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health"(WHO 2007). A health system is the basis for providing health services to communities. WHO developed a framework describing building blocks that interplay within a health system during delivery of health services, namely: governance, information, health financing, service delivery, human resources, medicines and technologies, and the people (community) that receives the services (Figure 4).

Figure 4: Health System building blocks by WHO
Source:(de Savigny et al. 2009)

Service delivery: A successful health system is expected to deliver safe and quality health services equitably, effectively and efficiently.
Health work force: should be in a position to achieve the best health outcomes. However, health personnel shortages are experienced worldwide due to the imbalance of skills, migration and poor distribution within and across countries, a negative work environment and a weak knowledge base (Chen et al. 2004).
Health information system: should ensure production of data that can be used to track health system performance and support decision making. For-instance, Malqvist et al., emphasized that improving reporting system for newborn deaths is a must for reducing neonatal mortality in low-income countries (Målqvist et al. 2008).

Essential medicines: In order to improve health, essential medicines must be readily available, affordable, of assured quality and properly used by the providers and patients. In Uganda, Pariyo et al., recommended that, for better quality of care for sick children, availability of essential medicines, vaccines, equipment among other factors, must be included in child survival policies and plans (Pariyo et al. 2005).

Finances: There is a need for effective allocation of financial resources for health to prevent catastrophe or impoverishment associated with having to pay out-of-pocket for them.

Health leadership and governance: refer to a wide range of functions carried out by governments to improve population health focusing on quality, equity in access to services and patient rights (WHO 2007).

Using this framework, Dickson et al., undertook a systematic assessment of the health systems in eight out of the thirteen countries with over fifty percent of the world's newborn deaths. They demonstrated that the most common constraints, or bottlenecks, to scale up maternal and newborn care interventions were linked to human resources, finance and service delivery. For example, lack of appropriate competent and equipped health work force to care for newborns, high out of pocket payment and poor quality of care. The strategies to hasten universal coverage of the essential interventions to reduce newborn deaths in resource-limited settings must therefore address shortages in health personnel, removal of financial barriers and improving access to care through innovative strategies like task shifting (Dickson et al. 2014) and use of CHWs (Kinney et al. 2010).

Context specific strategies are needed to strengthen the interaction of the six building blocks in a way that can result into more equitable and sustainable newborn care services across the continuum of care. Notably, health systems' strengthening is incomplete without community empowerment and the two should be linked to foster progress for newborn survival (Knippenberg et al. 2005; Lee et al. 2009). Countries that have reduced their newborn mortality rate to below 15 deaths per 1000 live births have employed strategies of offering both simple home-based care and facility care, with emphasis on care for small babies (Mason et al. 2014).

Mechanisms for referral of newborns at the community level

In situations where health care seeking practices are poor, community newborn referrals are critical to promote the contact of sick newborns with the health providers, given that newborn care is mainly facility based. Referring sick newborns to health facilities or treating them at home using community health workers is a strategy that has been used in resource-limited settings in Asia to avail newborn care and promote their survival (Bang et al. 1999; Baqui et al. 2008; Kumar et al. 2008; Darmstadt et al. 2010). However, the referrals can only be beneficial if the caretaker of the newborns complies with the advice given and completes the referral.

Different mechanisms for the referral of newborns exist at the community level (Figure 5). At the community level, newborn referrals have been initiated by community health workers, traditional birth attendants and clients themselves as reported in south Asia south Asia, sub-Saharan Africa and South America (Hoff 1992; Kalter et al. 2003; Baqui et al. 2008; Darmstadt et al. 2010). Facility-to-facility newborn referrals can occur from private clinics or lower health facilities to higher level facilities like the hospitals (Fidel Font et al. 2002; Peterson et al. 2004; Kallander et al. 2006).
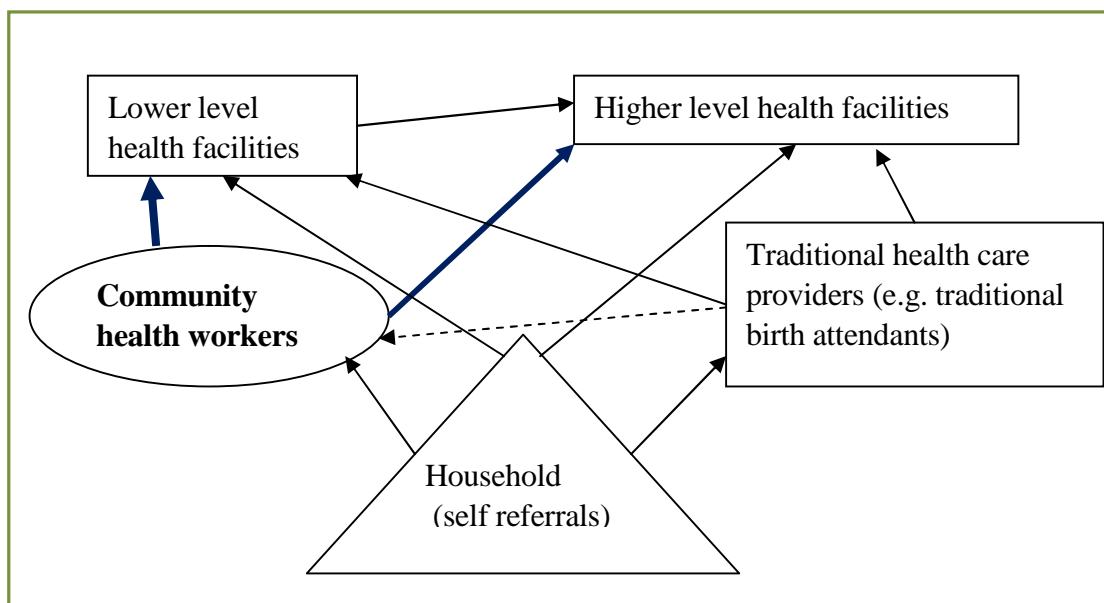
Figure 5: Newborn referrals by community health workers investigated in a study in this thesis shown by bold arrows.

Reasons for referral of newborns

The first seven days of life are the most risky and therefore, newborns demand special attention. Most referrals are likely to happen during this period due to danger signs that the babies may develop. In a study in this thesis, newborns were referred by trained community health workers during home visits for two reasons: i) newborns exhibiting at least one danger sign (that is, they were sick), and ii) a newborn who is well, but was born outside a health facility, for example at home, alongside the road, or at a traditional birth attendant's (TBA) home. Those found with a danger sign were referred for treatment, while those born outside the health facilities were referred for postnatal care including immunization. Newborns are delicate and vulnerable to infections such as sepsis and pneumonia and therefore need extra care, including proper cord care, thermal care and exclusive breastfeeding.

*Compliance with newborn referrals*

While different mechanisms for referral of newborns exist at the community level the performance of these processes, including compliance and its determinants, their effectiveness, and their impact on newborn survival, are not well studied in sub-Saharan Africa (Figure 6). Available data is for older children between 2 and 59 months. For example, in Uganda, Peterson et al., reported only 28% completion of referral among under-fives and 21% for children aged one week to 2 months being referred from lower level facilities to a higher level one under the Integrated management of childhood illness IMCI strategy (Peterson et al. 2004). In their study on the home-based management of fever, Kallander et al., reported 93% compliance rates for children under five referred from communities to health facilities (Kallander et al. 2006). Among newborns, Nsibande et al., reported a referral completion rate of 87 to 95% in South Africa (Nsibande et al. 2013) and a rate of 86% was documented by Kirkwood in Ghana (Kirkwood et al. 2013). In both studies, the determinants for compliance to the newborn referrals were not reported.

In a community trial in Bangladesh, 194 out of 609 (32%) neonates with very severe disease complied with referral advice by CHWs (Baqui et al. 2008). In another community trial in the same setting, Darmstadt et al., reported that 745 newborns received a total of 919 assessments by CHWs, for which referral was recommended and compliance was registered in 495/919 (54%) assessments (Darmstadt et al. 2010b) The low compliance figures imply that there are various barriers to overcome for effective newborn referral and these may also be different outside the Asian context. It is therefore important to explore newborn compliance in SSA where there is dearth of information on this subject, including in Uganda.

1.6.2 Capacity of health facilities to care for newborns

Dickson et al. found that management of the leading causes of newborn deaths - preterm and birth-related complications and infection - had the most bottlenecks across the health system building blocks (Dickson et al. 2014). District hospitals should be in the position to offer quality maternal and newborn care (Mason et al. 2014) but many times, that is not the case. Studies in SSA that have been conducted to assess the capacity of mainly higher level health facilities found them unsatisfactorily prepared to care for newborns (Opondo et al. 2009; Nesbitt et al. 2013; Vesel et al. 2013). The evaluation of the preparedness of health facilities to offer care to newborns, focusing on lower level facilities, is required, given that treatment procedures for newborns at higher level facilities may not be accessible by many families (Mbonye et al. 2012).
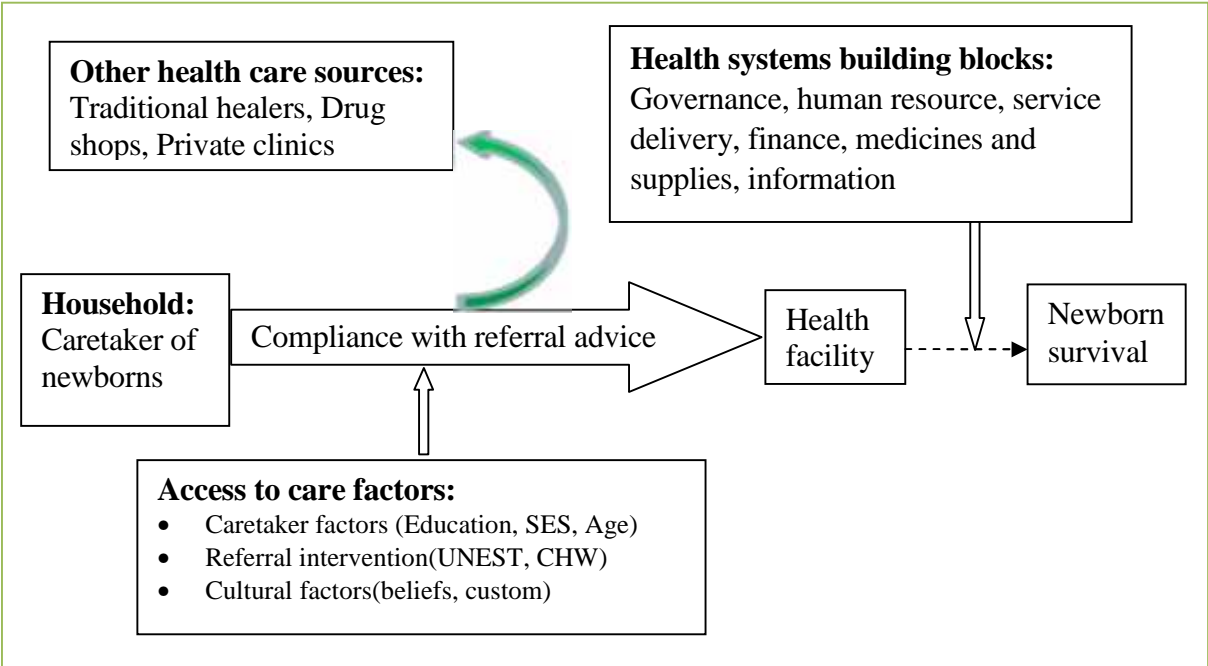
Figure 6: Access to newborn care and the health system

1.7 UGANDA PROFILE

1.7.1 Topography and population

Uganda is a landlocked country located in East Africa, bordering Kenya in the east, Rwanda and the Democratic Republic of Congo in the west, Sudan in the north and Tanzania in the south. With an average annual growth rate of 3.2%, the population is estimated to be about 36

million people, with 86% living in the rural areas. Life expectancy at birth was 56 years for men and 58 years for women in 2012. About 35% of the population lives on one dollar or less per day. The country has an area of 241,039 square kilometers and is administratively divided into 112 districts (UBOS 2012). The economy hinges on agriculture with the majority of the population practicing subsistence farming and others working in agro-based industries. The gross domestic product (GDP) is estimated at $ 504 US dollars and the economic growth rate averaged 7% per annum over the last 5 years (National Planning Authority 2010). The budgetary allocation to the health sector over the last 5 years has stagnated at about 9% of the national budget (MOH 2010b) compared to the 15% recommended in the Abuja Declaration (WHO 2011).

1.7.2 Uganda health indicators

Similar to global trends, maternal and older child mortality has significantly reduced in the last twenty years, unlike that of newborns which has slowly declined (Table 2). Uganda loses 18 mothers every day, and is unlikely to meet the maternal mortality MDG 5 target of 131 deaths per 100,000 live births. Although child mortality has declined over the last two decades, there are disparities, with higher mortality rates among children born to poor and rural families and to mothers with low education (MOH 2014).

Table 2: Maternal child and newborn indicators

Indicator	1990	2000	2012	Average annual reduction rate 1990-2012(3)	Percentage decline 1990-2012(3)
Maternal mortality ratio (death per 100,000 live births)	780	650	360 (*438)	3.20	53
Under 5 mortality rate (Deaths per 1000 live births)	178	147	69	4.3	61
1-59 months mortality rate (Deaths per 1000 live births)	136	110	45	5.0	67
Newborn mortality (Deaths per 1000 live births)	39	35	22	2.4	42
Proportion of under 5 death which are newborns	22%	-	33%	-	-
Total Fertility rate	7.1	-	6.0	0.8	-

*Source: Data compiled for A decade of change for newborn survival, policy and programmes (2000–2010)(Lawn et al. 2012) *Maternal mortality ratio reported in UDHS 2011*

1.8 UGANDA HEALTH CARE SYSTEM

1.8.1 Health service delivery

Uganda has a decentralized system of governance, with health care regionalized to districts and sub-districts. The central government has the responsibility of making policy, setting standards, and quality assurance. Health services are provided by the public, private not for profit (PNFP), private health practitioners (PHP), and traditional and complementary medicine practitioners (TCMPs).The private sector provides about 50% of all reported health services. In 2010, there were a total of 4,394 public and private facilities in the country (Table 3).

The health care system is graded, with Health Centre I as the lowest, up to National Referral Hospitals. Different care is provided at each level of the health system (Table 4) (MOH 2010c). Health Centre I has no physical structure but comprises the village health teams (VHTs). VHTs are community health workers selected by village members and are comprised of 5 to 7 lay persons who volunteer to promote health care in their respective communities. VHTs mobilize communities for health interventions such as immunization, malaria control, and sanitation, make home visits for newborns, promote health-seeking behavior, maintain birth and death registration, distribute any health commodities that are available from time to time, and serve as the first link between the communities and formal healthcare providers (MOH 2010c). Under the integrated community case management (iCCM) program, VHTs conduct home visits and refer sick newborns to health facilities (Kayemba C.Nalwadda et al. 2012).

The HCIIs provide the first level of interaction between the formal health sector and the communities, including the VHTs. The standard level staffing for a HCII is one Enrolled Nurse, one Midwife, and one Nursing Assistant. HCIIs only provide outpatient services, including the treatment of common illnesses, immunization, outreaches and referrals. HCIIIs promote recommended health practices, provide basic preventive and curative care, including delivery

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services and laboratory services, and provide support supervision to HCIIs under their catchment area, and offer first referral cover for a sub county. Health Centre IVs serve health sub districts with about 100,000 people. They provide out- and in-patient services, delivery care, minor surgeries and caesarean sections. Hospitals offer a wide range of services and are the referral units in the districts. The Regional hospitals and National Referral hospitals in the country offer comprehensive specialist services and are involved in health research and teaching.

The current number of health staff (doctors, nurses and midwives) is estimated at 59,000; including the PNFP sector (MOH 2010b). The staffing positions filled at health facilities went up from 56% in 2010 to 58%, in 2011 but this is still below the Ministry of Health target of 75% (MOH 2010b).

Table 3: Health facilities in Uganda 2010

Health facility Level	Health service provider			
	Government	Private not for profit	Private for profit	Total
Hospital	64	56	9	129
Health centre IV	164	12	1	177
Health centre III	832	226	24	1,082
Health Centre II	1,562	480	964	3,006
Total	2,622	774	998	4,394

Source: Adapted from Health Sector Strategic and Investment Plan 2010/11- 2014/15(MOH 2010b)

Referral system
The referral system in Uganda is based on the different levels of health care. At the community level, there are self- and VHT referrals. For example, through a community-based program, the VHTs visit newly delivered mothers, examine and initiate referrals for sick newborns. At health facilities, the healthcare provider in charge of the health centre refers the patients to a higher level and this can be continued until reaching the highest level of health care. Each level of health care is expected to acknowledge the referral by sending a feedback to the referring unit. However, in practice this is not always the case, creating an information gap about referral compliance of clients, including that of the newborns (MOH 2010b).

Table 4: Structure of the Uganda Health System.

Health facility level	Services provided	Location	Estimated Catchment population
HCI (VHTs)	Facilitate health promotion, community participation and utilization of services	Village	500
HCII	Outpatient services, community outreaches and linkages with village health teams (VHTs)	Parish	5,000
HCIII	Outpatient, maternity, general ward and laboratory services	Sub county	25,000
HCIV	Outpatient, maternity, general ward laboratory services theatre and blood transfusion	County	100,000
District Hospital	All services and radiology services	District	100,000-1,000,000
Regional Hospital	Specialized care, research and teaching	Region	5,000,000
National Referral Hospital	Comprehensive specialized care, research and teaching	National	35,000,000

Source: Adapted from Health Sector Strategic and Investment Plan 2010/11- 2014/15 (MOH 2010b)

1.8.2 Newborn care in Uganda

Nationally, newborn health care is coordinated by the Community Health Department under the Child Health Division in the Ministry of Health. The Community Health Division is supported by development partners, including WHO, UNICEF and Save the Children, who are also members of the National Newborn Steering Committee. Uganda has several policies in place to support improvement of maternal, newborn and child health in the country and some specifically target the newborn. These include the National Development Plan (NDP), the National Health Policy II (NHP II), the Health Sector Strategic Plan III (HSSP III), the Road Map for Accelerating Reduction of Maternal and Neonatal Mortality and Morbidity, the National Child Survival Strategy, and the Newborn Survival Strategy.

National development plan (NDP)
The National Development Plan (NDP) is the framework for the Government of Uganda (GoU) to guide development in all sectors for the period of 2010 to 2015. The overall goal of the NDP is to accelerate economic growth to reduce poverty. One of its development objectives is to increase availability and access to quality social services, of which health care is part, and prioritize programs to promote child survival. This frame work is used to incorporate newborn care strategies in relevant sectors (National Planning Authority 2010).

National Health Policy II (NHP II)
The National Health Policy (NHP II) covers a ten year period (2010to 2020) and was developed by the GoU, headed by the Ministry of Health. It was mainly informed by the NDP for the period 2010 to 2015. The focus of NHP II is on health promotion, disease prevention, early diagnosis and treatment of diseases. NHP II defines the Uganda National Minimum Health Care

Package (UNMHCP) that is made up of the most cost-effective priority health care interventions and services addressing the high disease burden that are affordable within the resources assigned to the sector. Maternal and child health are part of these priority areas as they contribute the highest proportion (20.4%) to Uganda's total burden of ill health and avoidable death. The NHP II emphasizes use of Primary Health Care (PHC) as the main strategy to deliver health services, and newborn interventions are included (MOH 2010a).

The Health Sector Strategic Plan III (HSSP III) 2010/11-2014/15
The HSSP III is a national framework that was developed to operationalise the NHP II and the health sector component of the NDP. Child health is one of the priority areas of HSSP III in addition to Reproductive Health, Health Education and the Control and Prevention of Communicable Diseases (HIV/AIDS, malaria and tuberculosis). This was meant to ensure that Uganda achieves MDG 4. The HSSP III includes the critical newborn care interventions that can be delivered through postnatal care interventions for mother and baby (MOH 2010b)

The Road Map for Accelerating Reduction of Maternal and Neonatal Mortality and morbidity in Uganda
Uganda is one of the 33 African countries that have adapted and developed a national maternal newborn health Road Map (UNFPA 2009). It was developed by the Ministry of Health with support from development partners. The Uganda Road Map defines the course of action the GoU and her development partners should take to hasten the reduction of maternal and neonatal mortality and morbidity. It focuses on promoting skilled care during antenatal care, delivery and postnatal care services and encourages health seeking behavior by community members. Implementation of the Uganda Road Map is a multi-sectoral effort coordinated by the Ministry of Health (MOH 2009b)

National Child Survival Strategy
The National Child Survival Strategy (CCS) was formulated in 2007 to address the main barriers of child health interventions at household and community level. The overall aim of the strategy is to reduce the less than five mortality rate from 137 per 1,000 live births to 56 per 1,000 live births by 2015. The strategy also prioritizes newborn health and emphasizes that it is critical to reach every newborn and child with high impact interventions in order to make rapid progress towards attaining MDG 4. The strategy proposes the use of trained CHWs to initiate referrals of sick newborns to health facilities (MOH 2009a)

Newborn Health Implementation Framework: Standards for Newborn HealthCare Services
This framework was developed in 2010 by the Ministry of Health. It defines capacity and expected quality of care for newborns in terms of inputs, processes and outcomes related to newborn health. The standards are categorized into infrastructure, equipment and supplies, Information, client factors, management systems, clinical services, infection prevention and village health teams (MOH 2010c)

Uganda Essential medicines and Health Supplies list
Essential medicines are described as those medicines that satisfy the health care needs of the majority of the population at a price patients and the community can afford (World Health Organization 2006). The essential medicines should be available at all times, in adequate amounts, and in appropriate dosage forms. The current Uganda Essential Medicines and Health Supplies list developed in 2012, does not list newborn sepsis drugs (injectable gentamycin and

ampicillin) for use at Health Centre II level but rather at Health Centre III and higher level facilities (MOH 2012).

A Promise Renewed: Reproductive Maternal, Newborn and Child Health Sharpened Plan for Uganda

In line with the global initiative to reduce child mortality by 20 deaths per 1000 live births by 2035, the Ugandan government, with its development partners, has developed a sharpened reproductive, maternal, neonatal and child health (RMNCH) plan to accelerate progress towards achieving MDG 4 and 5 (MOH 2014). This plan focuses on mobilisation of resources, prioritisation and implementation of high impact interventions to attain the necessary impact by 2015. The plan is also aligned with the National Development Plan for 2010/11- 2014/15 and proposes five strategic shifts to end preventable maternal and child deaths. These are:

- Geographically increase the focus and effort at districts with the highest number of under-five deaths
- Refocus districts to prioritise and scale up access to services to highly burdened populations
- Focus on high impact solutions
- Focus on environmental sanitation, education of girls and women, and empowerment of women, both economically and in decision making
- Mutual accountability for any results at all levels of the health system

The plan recognizes that priority interventions with the highest impact in averting maternal and child mortality are known, and are mainly centered around labour and delivery management. Focus will be on these priority interventions and if implemented, it is estimated that over a period of four years (2014-2017) child and maternal mortality will be reduced by 40% and 26%, respectively (MOH 2014).

1.9 HEALTH SEEKING BEHAVIOR MODELS

Health seeking models attempt to explain how, when and why persons seek health care. Mackian et al., suggested two main approaches to health seeking behavior:1) health seeking behavior which centers on the process of responding to illness, and 2) health care seeking which focuses on the act of seeking health care (Mackian et al. 2004).

Models explaining health seeking behavior

Health belief model (HBM): It depends on health motivation and is based on six main constructs that will influence people to seek. The people will act if they believe they are susceptible to a condition (*perceived susceptibility*); the condition has serious consequences (*perceived severity*); taking action will reduce susceptibility (*perceived benefit*); the benefits outweigh the (*perceived barriers*); they are exposed to factor that prompt action eg media adverts (*cues of action*) and are confident they will perform the action (*self efficancy*) (Janz et al. 1984).

The Theory of Planned Behavior (TPB) and Theory of Reasoned Action (TRA): These two models are closely related and hinge on behavioral intention, which is influenced by the persons attitude towards performing a behavior, beliefs about whether a significant other will approve or disprove the behavior (subjective norm) and the belief that the person can control situations (perceived behavioral control) (Ajzen et al. 1977).

The limitation with the health seeking models is that they focus on the patient (demand side) as the pivot for the success or failure of the treatment and do not take into account the health care provider factors (supply side). In addition, they neither consider emotional   attributes in decision making nor the gender and power issues.

Models explaining healthcare seeking behavior
The four As model: It was developed to assist explore health care seeking behavior with the intention to promote equitable access to care (Andersen 1995). The key attributes are as follows: Geographical distribution of the sources of care that are able to meet the client's need (availability), easy of the client to reach the health service provider, eg roads and transport, physical access (accessibility), ability of households to pay for health services (affordability) and cultural and social appropriateness (acceptability) of the health care

Pathway models: Based on constructs of perception of the illness and significant others for choice of treatment. It also considers duration of the illness, knowledge and expenditure as factors influencing choice and switching of therapy (Nyamongo 2002).

The three delays model: This model was developed in an exploration of the factors that contribute to maternal mortality, in a systematic way from the onset of the maternal complication to the period of receiving appropriate care. The model proposes three stages during which delays can occur: Stage 1- delay to recognize illness and make decision to seek care (Delay 1). The second delay is to reach the health facility (delay 2) and delay in receiving quality care at the health facility (Delay 3) (Thaddeus et al. 1994) .

This research work builds on previous work of understanding newborn care in Uganda (Waiswa 2010b) where the author used the three delays model (Thaddeus et al. 1994) to explore the causes of newborn deaths. The work in this thesis examined caretakers' compliance with community newborn referrals and the related aspects in a broad picture of improving newborn outcomes. Compliance with community referrals is a multi-facet outcome affected by individual, community and health system factors. I therefore choose the three delay model to explore the interaction of these factors.
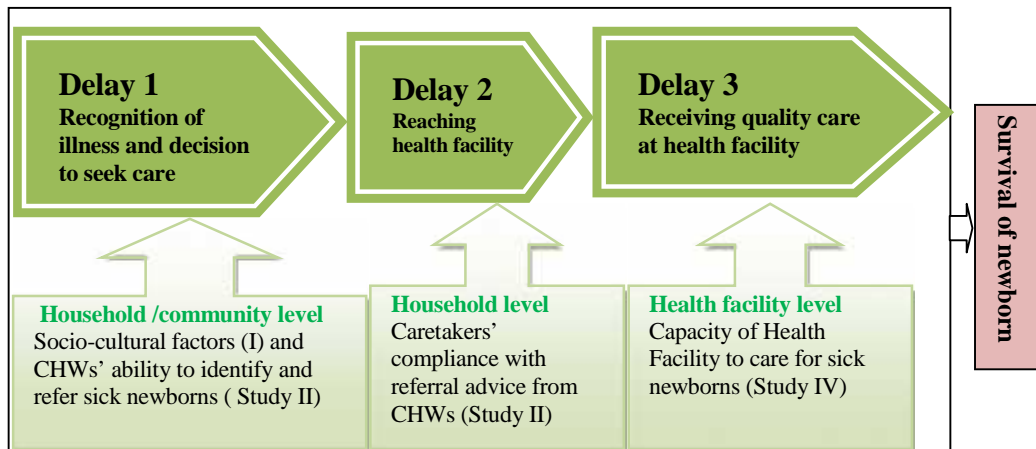
1.10 CONCEPTUAL FRAMEWORK FOR THE THESIS

In this thesis, the three delay model was used to examine community and household factors that could affect compliance with community newborn referrals and the provision of newborn referral care in health facilities. Compliance to referral advice has been reported to be affected by caretaker's their ability to recognize and the way they perceive the severity of the illness (Simba et al. 2009; Nsibande et al. 2013) which can be related to socio-cultural factors (Study 1). Through home-visits CHWs were found to promote newborn survival (Baqui et al. 2008).The CHWs' ability to recognize and refer sick newborns (Study II) can influence caretakers' compliance with referral by counseling and alerting the caretakers of the presence of disease among the newborns as well as influence caretaker's decision to seek referral care.

Reaching the health facility commences with the caretaker complying with the referral advice given to him /her by the CHW (study III). Availability of competent health workers and adequate equipment and supplies (study IV) can influence the timeliness and quality of newborn

care provided at the health facilities and subsequently the newborn outcome (Figure 7). This model will also be used to discuss the findings of this research work at a later stage after the results section.

Figure 7: Conceptual framework for the thesis adapted from Thaddeus and Maine's Three Delays model (Thaddeus et al. 1994)

1.11 SUMMARY OF KEY KNOWLEDGE GAPS

Over the last twenty years, there has been a global reduction in the deaths of older children aged (1 to 59 months) but with a smaller decline in newborn mortality. But there is a dearth of context-specific data to inform strategies to reduce newborn mortality, particularly in SSA.

As a strategy to improve newborn survival, WHO and UNICEF recommend home visits for newborns during the first week of life, and counsel caretakers to seek referral care for their sick newborns at health facilities. However, there are few studies that have focused on understanding the socio- cultural beliefs and practices that would affect caretakers' compliance with such referrals in SSA. This data is critical in designing context-specific strategies to achieve the desired impact.

The policy to conduct home visits to newborns puts an additional work load on the already constrained and scarce healthcare workforce in low income countries. For instance, in Africa where there are majority of countries with the highest burden of newborn mortality (more than 15 newborn deaths per 1000 live births), the health worker population density is 2.3per 1000 population compared to Europe (18.9/1000) with low newborn mortality (WHO 2006). As a solution, CHWs have been used in some countries to conduct home visits and home-based care for children under five, but there is limited information regarding CHW's accuracy in neonatal assessment to identify and refer sick newborns, particularly in the first week. This data is also needed before scaling up community-based programs that use CHWs.

Several studies have evaluated newborn preventive care practices in SSA (Bazzano et al. 2008; Byaruhanga et al. 2008; Waiswa et al. 2010), while a few have assessed newborn referral practices and compliance in this region (Kirkwood et al. 2013; Nsibande et al. 2013). However, there is still an information gap regarding factors associated with the caretakers' compliance to the referrals.

It is not enough to increase demand for newborn care services through community referrals without ensuring that health facilities have the capacity to care for the newborns, of which there is little information currently available. The available information is limited to hospitals and higher level health centres, but data is required for first level facilities, where the majority of caretakers are likely to seek referral care for newborns.

1.12 PROBLEM STATEMENT

About 134 newborns die per day in Uganda (Lawn et al. 2012; Mbonye et al. 2012), mainly of prematurity complications (Liu et al. 2012) yet simple, cost effective interventions that already exist could avert over 60% of these deaths, if universally implemented (Darmstadt et al. 2005; Martines et al. 2005). Facilitation of newborn referrals through CHWs at the community level to increase their contact with the health care providers is one of the strategies that has been shown to have an impact on newborn mortality (Baqui et al. 2008; Bhutta et al. 2009; Gogia et al. 2010; Darmstadt et al. 2010b; Kirkwood et al. 2013). However, this can only happen if the caretakers of the newborns comply with the referral advice and the receiving health facilities are able to effectively care for such newborns.

There is limited information on newborn referral practices and compliance in SSA (Kirkwood et al. 2013; Nsibande et al. 2013). Most of the available evidence is from Asia (Baqui et al. 2008; Darmstadt et al. 2010a) where community newborn referral compliance has been shown to be only 32% (Baqui et al. 2008) and 54% in Bangladesh (Darmstadt et al. 2010b). Some of the factors that may influence compliance for newborn referrals include caretakers' perception regarding symptoms and signs of the illness, age of the newborn, and the severity of the illness of the child (Darmstadt et al. 2010b)

This thesis evaluated newborn referrals within a community-facility linked intervention, with a specific focus on the levels of compliance and determinants for newborn referrals by CHWs in SSA. Furthermore, the study explored socio- cultural beliefs and practices during the newborn period, CHWs' ability to identify and refer sick newborns and the preparedness of health facilities to provide care to sick newborns. The findings are meant to contribute to policy formulation for newborn care in Uganda and other similar settings.

1.13 RATIONALE FOR THE STUDIES

In Uganda, the National Child Survival Strategy (MOH 2010c), aims at ensuring that health services reach every newborn and child with high impact interventions to accelerate progress towards attainment of MDG 4 (MOH 2009). As part of the strategy to achieve this, the Ministry of Health and its partners trained village health teams (VHTs) to initiate referrals of sick newborns from communities to health facilities (Kayemba C.Nalwadda et al. 2012). However, several issues surrounding newborn referral, including compliance and its determinants, are not well understood in Uganda. Secondly, it is not clear how community-based approaches should be rolled out or balanced, once introduced in the public sector systems (Nair et al. 2010).

This thesis attempts to answer some of these questions and evaluate referrals of newborns facilitated by CHWs with a focus on understanding the community's perceptions and practices during the newborn period, the role of CHWs in promoting utilization of facility-based care for newborns, the levels of compliance by caretakers and its determinants, and the capacity of

health facilities to care for newborns. The findings will partly provide baseline information to inform policy and rolling out of newborn care programs.

2 AIM AND OBJECTIVES

2.1 GENERAL OBJECTIVE

To assess newborn referral care-seeking practices, compliance, and associated community and health systems factors, in order to inform scale-up of newborn care programs in Uganda and beyond.

2.2 SPECIFIC OBJECTIVES

1. To understand the community's perspective of potential socio-cultural barriers and facilitators to compliance with newborn referral **(I)**

2. To determine community health workers' competence to identify and refer sick newborns **(II)**

3. To determine the compliance rate and associated factors among caretakers of referred newborns (**III)**

4. To assess the capacity of health facilities to offer care to sick newborns **(IV)**

3 MATERIALS AND METHODS

3.1 STUDY SETTING

All the studies in this thesis were conducted within Iganga-Mayuge Health and Demographic Surveillance Site (HDSS), located in the two districts of Iganga and Mayuge in eastern Uganda (Figure 8). The districts lie approximately 120 kilometres east of Kampala, the capital city of Uganda. The Iganga-Mayuge HDSS comprises 13,000 households spread across 65 villages, with a population of about 80,000 people, of which 45.9% are aged below 15 years. The HDSS is predominantly rural, except 13 villages that form Iganga town council which is peri-urban. The largest ethnic group in the area is the native *Basoga,* forming 80% of the population. The main dialect used is called *Lusoga.* The population mainly practices subsistence farming and fishing, among other occupations like small scale business, and civil service employment (HDSS 2011). There are 14 public health facilities in the HDSS including one district hospital, and the rest are lower level facilities. About 68% of deliveries occur at health facilities and 71% are attended by skilled health workers, including private midwives (UBOS 2011). The NMR is estimated at 22.2 deaths per 1000 live births (HDSS 2011).
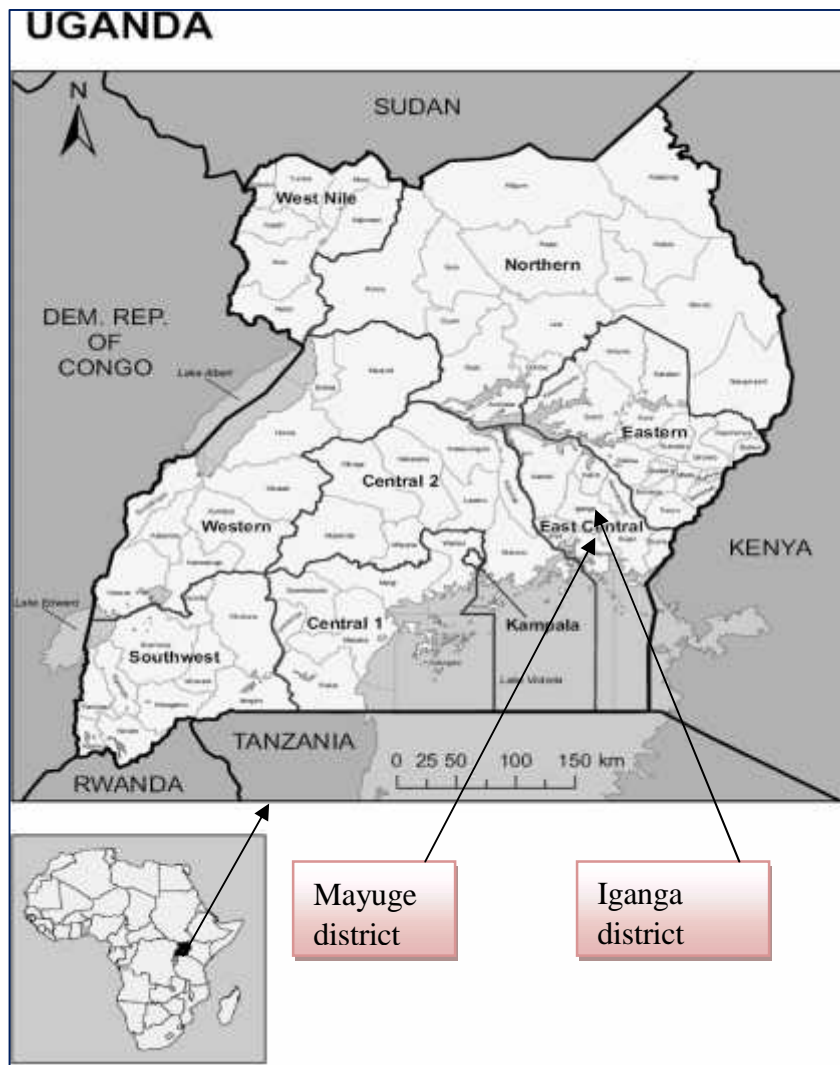
Figure 8: Showing study site districts

3.2   THE UGANDA NEWBORN STUDY (UNEST)

All the studies in this thesis were nested within a larger project, the Uganda Newborn Study (UNEST), also conducted within the Iganga-Mayuge HDSS. The UNEST project was a cluster randomized controlled trial (cRCT), which started in December 2008 and ended in May 2012. The intervention was implemented from September 2009 and ended in August 2011. The overall goal of the project was to test an integrated maternal-newborn care package that linked community and facility care, and to evaluate its effect on maternal and neonatal outcomes in Iganga and Mayuge districts (Waiswa 2010). The package included recruitment, training, and regular supervision of community health workers (CHWs), health facility strengthening through training of health workers, the provision of some supplies and equipment to health facilities , and conducting home visits to pregnant and newly delivered mothers by CHWs as shown in Panel 2. The CHWs were literate volunteers, both men and women, nominated by their respective village members. They were trained for 5 days by a team comprised of UNEST staff, health workers, Iganga and Mayuge district health team members and trainers of maternal and newborn care from the Ministry of Health. The members of the training team regularly supervised the CHWs.

3.3   STUDY DESIGN AND STUDY POPULATION

Four studies (I-IV) were conducted between 2011 and 2013 at the Iganga-Mayuge Health Demographic Surveillance Site in eastern Uganda. Both quantitative and qualitative methods were employed to collect data guided by the specific objectives of the studies.
Study I was a across sectional study where focus group discussions (n=12) with men and women and in-depth interviews (n=11) with mothers and traditional birth attendants were used to obtain a deeper understanding of the social and cultural factors that affect caretakers' compliance with community newborn referrals.

In Study II, case vignettes, observations through role plays and record reviews were used in a cross sectional study to assess the ability of 57 trained community health workers to identify and refer sick newborns to health facilities.

Study III was a retrospective cohort, where all referred newborns and their caretakers were listed from the CHWs registers and traced to their homes. Out of a total of 724 referred newborns, face to face Interviews were held with caretakers of 700 newborns   who were successfully located to their households to determine their compliance rate, and associated factors. Compliance was defined as a caretaker s visiting health facility within 24 hours of referral. Non- compliance was defined as visiting the facility after 24hours or not going at all.

In study IV, a cross-sectional study was used to assess the capacity of all the health facilities targeted by UNEST for strengthening. A total of 20 health facilities at different levels of primary health care to provide care to sick newborns were studied. .They included: one district hospital; one level IV health facility that offers out- and in-patient care, caesarean section and minor surgery; six level III health facilities that offer in-patient and delivery facilities; and 12 level II health facilities that offer only out-patient services. A total of ninety-two health workers at these facilities also participated in face-to-face interviews and observations. Fifty of these health workers were assessed for knowledge and 42 were assessed for newborn resuscitation skills.
An overview of the four studies in this thesis is presented in Table 5.

Figure 9: The Uganda Newborn Study (UNEST)

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A) Description of Uganda Newborn Survival Study (UNEST)

Objective:

To test an integrated maternal-newborn care package that links community and facility care and evaluate its effect on maternal and neonatal outcomes in Iganga and Mayuge districts (Waiswa et al. 2012).

Study design:

A cluster randomized trial in 32 control and 31 intervention villages, located in a Health Demographic Surveillance Site with about 80,000 people in eastern Uganda.

Intervention package:

- Health facility strengthening: Trained health workers and provided a one time off supplies and equipment to strengthen maternal and newborn care services in 20 health facilities. These facilities included the 14 within the HDSS and 16 others outside the HDSS.
- Training : Sixty one CHWs were trained to link communities and health facilities by:
  1) CHWs paying two visits to pregnant mothers and three visits during the first week after birth
  2) CHWs referring mothers and newborns found with danger signs and those born outside facilities for immunization and postnatal care.
- Innovative CHW supervision: CHWs were regularly supervised by health workers from public health facilities using, directly observed supervision (DOS) approach. In the DOS approach, the supervisors accompanied the CHWs to the communities for the home visits. A supervisor observed a CHW interacting with the mother and baby uninterrupted. At the end of the home – visit, the supervisor held a closed session, pointed out and reinforced the weak areas of the CHW.

B) Content of the training provided to CHWs regarding newborn care included:

- Cord care
- Thermal care
- Breast feeding and initiation
- Kangaroo mother care
- Newborn danger signs
- Newborn referral

Adapted from UNEST protocol (Waiswa et al. 2012)

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Table 5: Overview of the four studies in the thesis.

Study dimension	Research question	Study population	Data sources	Paper
Understanding compliance to newborn referrals	What are the socio-cultural factors affecting compliance with newborn referrals?	Community members (men, women and traditional birth attendants)	FGDs (n=12) IDI (n=11)	I
Knowledge and skill	Following training, can CHWs identify and refer sick newborns?	Community health workers (CHWs)	Case vignettes, observation of role plays and interviews with CHWs n=57	II
	Are the health workers competent in care for newborns?	Health workers	Interviews (n=50) Skills assessment (n=42)	IV
Compliance to newborn referrals	What is the compliance rate? What are the factors associated with compliance?	Caretakers of newborns	Census of all newborn referrals (n=700) Interviews with caretakers of 700 newborns	III
Provision of care	Do health facilities have the capacity to care for newborns?	Health facilities	Observations and interviews at health facilities (n=20)	IV

3.4   DATA COLLECTION METHODS

3.4.1 Socio-cultural factors influencing community newborn referral (I)

The aim of this study was to understand socio-cultural factors that can influence compliance to community newborn referrals. In order to do this, focus group discussions (FGDs) (n=12) and in-depth interviews (IDI) (n=11) were conducted with mothers, fathers and TBAs. FGDs and IDIs are qualitative methods that are good for exploring peoples' perceptions, knowledge, feelings and experiences, and for answering questions about what, how and why, and can be used with illiterate or literate persons (Kitzinger 1995; Bryman 2004). The thematic areas explored included the community understanding of a newborn, norms, perceptions and practices during the newborn period which might impact on danger sign recognition, care-seeking practices and decision making processes, and referral compliance.

Recruitment of study participants
In order to obtain diverse opinions, 12 villages were randomly selected from the 65 villages of the HDSS and a FGD was hosted in each one. The FGDs were categorized by location, gender (male or female) and residence (peri-urban or rural). The rationale behind categorization was to

obtain maximum variation in the views of the study participants. The participants were purposively selected to participate in the FGDs and IDIs. The participants were required to have children aged less than 3 months in order to identify individuals with the current norms and practices surrounding newborn care in this setting. From the same 12 villages, e IDI participants, that is TBAs and mothers who had experienced referral of their babies during the newborn period were selected. The mothers were categorized according to compliance with referral; that is, those who complied and those who did not. IDI were undertaken as part of data triangulation using the within-method approach as described by Denzin, (Denzin 1970) to increase credibility of the findings from independent data sources (Decrop 1999).

Discussions and interviews
The venues for the discussions and interviews were agreed upon by the participants, such as, their homes and community centres. FGDs and IDIs were conducted in Lusoga, the main local dialect, by research assistants whose first language was Lusoga. The assistants were experienced in qualitative data collection methods as note takers or moderators. They were trained on study objectives and familiarized with the discussion and interview guides prior to data collection. The study tools were pretested based on questions formulated according to themes from previous research findings, but remained flexible to address emerging issues during interviews and discussions. All the discussions and interviews were tape recorded. The note takers immediately expanded the notes after the interviews and discussions, in preparation to supplement recordings at a later date in cases where the recordings were not audible during the transcription. Emerging issues were identified and explored further in the subsequent interviews.

Figure 10: Focus group discussion with women during data collection in Paper I

3.4.2 Community health workers' ability to identify and refer newborn (II)
In this study, CHWs were assessed for competence to identify and refer sick newborns. Competence was defined as having three attributes: knowledge about newborn dangers signs, the skill to recognize a newborn with a danger sign and the ability to effectively communicate with the caretaker about the danger signs, and counseling the mothers to seek referral care for their newborns from health facilities. Therefore, three methods of data collection were utilized: i) interviews to assess the knowledge of the CHWs about the danger signs using a semi-structured questionnaire, ii) interview of CHWs to assess their ability to identify a newborn with a danger sign using case vignettes, iii) observation of CHWs to assess their communication skills using role plays.

i) CHWs knowledge about danger signs

A semi-structured questionnaire was used to collect socio-demographic characteristics of CHWs in addition to asking them to mention five newborn danger signs they knew (unprompted) and to indicate whether a named symptom was a newborn danger sign or not, by stating true or false (prompted). There were a total of 11 danger signs for the prompted questions (Figure 11). A correct answer was awarded one point and no points for an incorrect one, making the minimum score 0 and the maximum score 16. A CHW was considered knowledgeable if (s)he obtained all 16 points.

ii) CHWs' ability to identify a newborn with a danger sign using case vignettes

A case vignette is a hypothetical narration created to depicted a desired scenario for various purposes such as examining knowledge, attitude or opinions (Gould 1996). Case vignettes have been found to be valid in measuring competence of physicians and quality of care (Peabody et al. 2000). They have also been used to measure competence of health workers in managing serious illness among infants (Gouws et al. 2005). Four case vignettes were developed using the clinical notes of newborns cared for in a district hospital, with three depicting a newborn with danger signs and one without danger signs. The case vignettes were complemented with pictures showing newborn-specific danger signs to ensure that the CHW understood the newborn in the description. Individually, each of the CHWs was asked to mention whether the newborn in question had a danger sign or not and if so point out the danger sign(s). A total of eleven danger signs were embedded in the case vignettes.

iii) Observation of CHWs to assess the communication skill using role plays.

Role plays have been positively evaluated as method for learning about communication in medical education (Tompkins 1998; Wagner et al. 2002; Nestel et al. 2007). A mother with a baby in the late newborn period was identified in the study area and coached to participate in the role play and report to the CHW that the newborn had a fever and the umbilical cord was smelly with pus. CHWs were instructed to assume that the description of the condition of the newborn by the mother was correct. Using a pre-designed checklist, the study researchers observed and took notes of every CHW's action as she/he communicated with the mother. Ten communication aspects (Figure 11) were assessed and each of these aspects was scored one point if done and no points if not done. Every CHW was expected to perform all ten communication attributes. CHWs were also expected to request a pre-designed referral form from the researcher and complete it to refer the newborn. The quality of the filled referral form was then assessed.

Figure11: Case vignettes used in the assessment of the skills of CHWs to identify newborn danger signs.

Case-vignette 1: During your work as a CHW, you visit a home with a 3 day old baby boy. The mother seems worried because the baby has been persistently crying and has **failed to suckle** in the last 24 hours. When you check on the baby you find that the cord is still attached but with a **smelly fluid oozing** out and parts of the baby's body are covered with **pustules.**
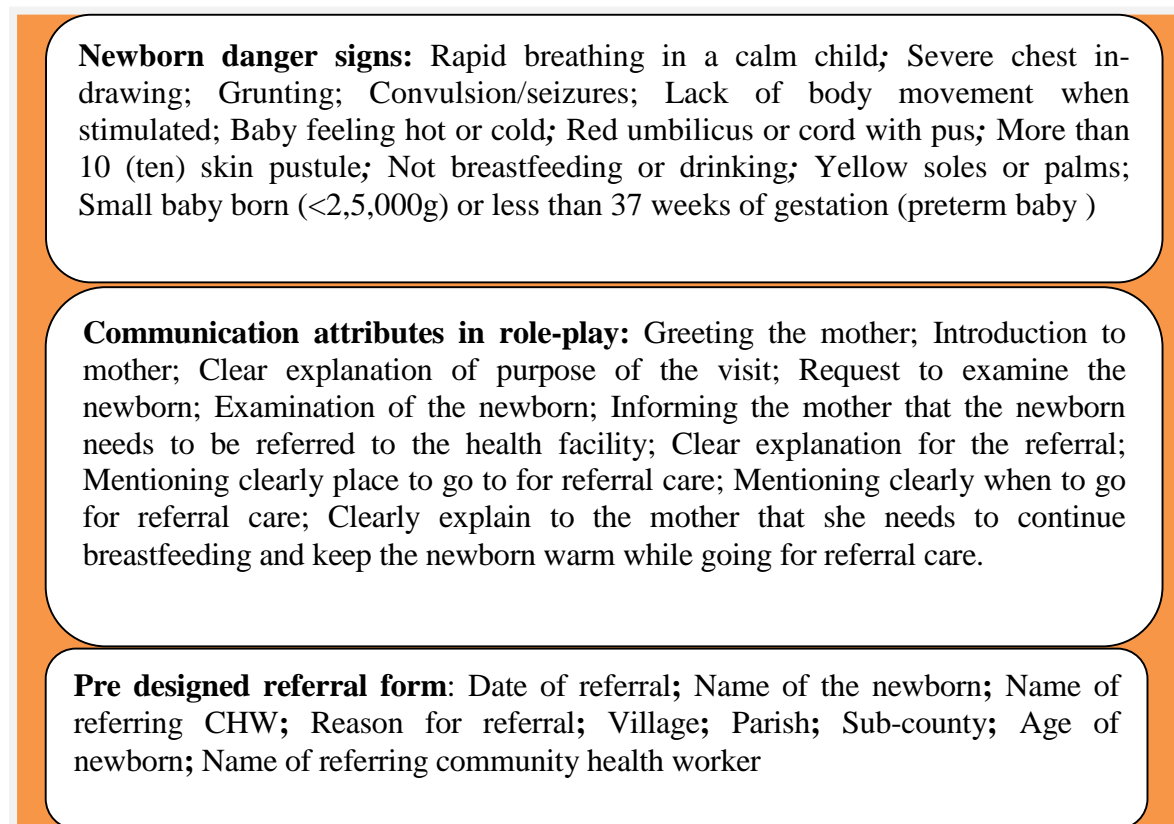
Case-vignette 2: A father of a newborn in your work area comes and reports to you that his 3 week old baby is not well. You quickly go to check on the baby and you are told that the baby cries a lot but keeps quiet after suckling. The mother complains that the baby wants to suckle all the time and feeds over 10 times in a day. The mother is very worried and concerned about the condition of the baby. (**No danger signs in this scenario, baby is not sick**)

Case-vignette 3: As part of your responsibilities, you go out to visit one of the families with a newborn. You are told that the baby is well apart from **feeling very hot** and also pushing its head backwards. When you ask to be shown the baby you find that the **baby's neck and limbs are difficult to move** but keep jerking. The baby also looks **very pale** and is **small, weighing about two kilograms.**

Case-vignette 4: You receive the news that one of the mothers in your work area delivered the previous night. You prepare and go to visit the family of the newborn. You request to see the baby. When you hold and look at the baby, its eyes are closed, it has **no power in all the limbs,** has **difficulty in breathing** and **feels cold.** However, the mother says that she had no problem during delivery and the baby is well.

Note: Only the underlined symptoms and signs we considered as danger signs in this study

Figure 12: The newborn danger signs, referral form and communication attributes assessed for in Paper II

Newborn danger signs: Rapid breathing in a calm child*;* Severe chest in-drawing; Grunting; Convulsion/seizures; Lack of body movement when stimulated; Baby feeling hot or cold*;* Red umbilicus or cord with pus*;* More than 10 (ten) skin pustule*;* Not breastfeeding or drinking*;* Yellow soles or palms; Small baby born (<2,5,000g) or less than 37 weeks of gestation (preterm baby)

Communication attributes in role-play: Greeting the mother; Introduction to mother; Clear explanation of purpose of the visit; Request to examine the newborn; Examination of the newborn; Informing the mother that the newborn needs to be referred to the health facility; Clear explanation for the referral; Mentioning clearly place to go to for referral care; Mentioning clearly when to go for referral care; Clearly explain to the mother that she needs to continue breastfeeding and keep the newborn warm while going for referral care.

Pre designed referral form: Date of referral**;** Name of the newborn**;** Name of referring CHW**;** Reason for referral**;** Village**;** Parish**;** Sub-county**;** Age of newborn**;** Name of referring community health worker

3.4.3 Compliance with newborn referral and determinants (III)

Using the trained CHWs' records (newborn referral registers), all newborns that were referred by the CHWs during the UNEST intervention were listed. A total of 724 were listed and 700 were successfully traced; the rest had moved to unknown addresses. Face-to-face interviews were conducted with the caretakers of the newborns using a semi-structured questionnaire. Data was collected on : i) caretaker and head of household socio-demographic characteristics, ii) sex of the newborn, iii) date and age of the newborn at referral (obtained from the referral form), iv) number of CHW visits to mother during and after pregnancy, v) place of delivery of the newborn, vi) clinical characteristics of the newborn at the time of referral, vii) reason for referral of the newborn (obtained from the referral form), viii) compliance with referral advice given by CHW, ix) reason(s) for non-compliance, x) follow up visit to referred newborn by CHW, xi) place where referral care was sought, xi) distance to the place where referral care was sought, and xii) household ownership of selected assets for classification of social economic status (SES) of the newborn household. The questions were adopted from existing validated tools from Save Newborn Lives (SNL) and also used in UNEST.

3.4.4 Health facility capacity to care for sick newborn babies (Paper IV)

In this study, data was collected from health facilities and health workers. Data were collected by two public health specialists and three research assistants with nursing training. These collected data for health facility assessment and conducted interviews on health worker

knowledge in newborn care. Two pediatric consultants conducted the newborn resuscitation skill assessment among the health workers using dummy babies.

Health facility assessment

Twenty health facilities at different levels of primary health care, targeted by UNEST for strengthening (Panel 2), were selected for assessment for readiness to care for sick newborns. They included one district hospital, 2 Health Centre IV, six Health Centre III, and twelve Health Centre II. The focus was on the main causes of newborn deaths: preterm and low birth weight-related complications, birth asphyxia and infections (Lawn et al. 2005; Black et al. 2010; Liu et al. 2012; UNICEF et al. 2013a). Using a modified version of the "Newborn Rapid Health Facility Assessment Checklist" developed by the Inter-agency Newborn indicators Technical Working group of Healthy Newborn Network (HNN)(Health newborn network 2012), data were collected on the following indicators: newborn service availability, equipment and supplies, documentation, trained staff and supervision (MOH 2010c).

Health worker assessment

 A total of ninety-two health workers at these facilities also participated in face-to face interviews; fifty health workers were assessed for knowledge and forty-two assessed for newborn resuscitation skill. The assessments took place two weeks apart and not necessarily on the same persons.

Health workers were assessed on knowledge of newborn care using a tool adapted from UNEST training materials. The tool consisted of three sections about essential newborn care services, corresponding to the main causes of newborn mortality; i) preterm birth complications/low birth weight; ii) birth asphyxia and iii) infections. The tool had a total of 64 multiple choices questions equally weighted. A correct answer was awarded 1 point and an incorrect one 0 points. Thus the minimum score for knowledge was 0 and the maximum was 64 points

Health workers were also assessed on newborn resuscitation skill with an Ambu bag and mask technique on a mannequin baby. The skills assessment for resuscitation of newborns was conducted among health workers who had participated in newborn resuscitation training between January 2009 and December 2011, during the implementation of UNEST project. The checklist used to collect data was adapted from the UNEST training materials. The total score was 23 points based on the items in the assessment.

3.5   DATA ANALYSIS

3.5.1 Study I

The research assistants who conducted the FGDs and IDIs transcribed the recordings verbatim, direct from the local language (Lusoga) into English. The transcripts were read through by the principal researcher in consultation with the research assistants to ensure that all recordings were transcribed fully. The transcripts were assigned identification numbers and the socio demographic data of the participants entered into the computer and analyzed in STATA version 10.

The transcripts were uploaded into a qualitative data management software programme (ATLAS.ti version 7.0) for coding and analysis. Three research team members read the transcripts independently to generate codes that were used to develop the code book. The text was coded into meaning units, which were coded into condensed meaning units, then assigned an interpretation of underlying meaning and grouped into categories as described by Graneheim and Lundman (Graneheim et al. 2004). The categories were then grouped into sub-themes. This analysis process (Table 6) was led by the principal investigator, guided by the medical anthropologist.

Table 6: Qualitative data analysis of the FGD and IDI feedback transcribed verbatim

Text/ verbatim extract	Meaning unit	Condensed unit	Sub- theme	Themes
We call the baby 'nakaghwele'. 'Nakaghwele' is the newborn and 'omwibo' is the mother. Because she still in the postnatal period 'akali mwibo'	'Nakaghwele' is the newborn and 'omwibo' is the newly delivered mother	Cultural terms for newborn and mother	Newborn and mother cultural terms	Understanding newborn definition
'Nakaghwele' starts at one day up to: 6 weeks..., 3 months..., 6 months when he starts eating and drinking..., starts to crawl/ walk..., ends at 2 years..	Newborn period defined in various ways	Varying definitions of newborn in community	No common newborn definition	Understanding newborn definition
Now, we the Basogas have cultural norms..., A baby with an umbilical cord does not come out of the house and doesn't cross the road unless when sick.	A baby with an umbilical cord does not come out of the house	Newborn kept in house till umbilical cord detaches	Seclusion period	Understanding newborn period and cultural expectation
It's to all, irrespective of boy or girl; the cord must go off before he is brought out of the house	Both female and male newborns are kept inside until cord detaches	Male and female babies treated the same	Seclusion norm - no differentiation by sex	Understanding newborn period and cultural expectation
If Sande (CHW) gives me a referral form, I don't line up; when I reach there, I just show them the referral form and they will work on me; you don't have to wait like the one without a referral form.	Mothers referred by CHWs with a referral note are attended to quickly at health facilities	CHWs referrals recognized by health workers	CHW link mothers to health facilities	Role of community health actors
No, we go there because clinics are near and easy to access. And still it depends on the baby's situation; you may just go and get first aid from clinics before you proceed to the hospital.	Seek care from private clinics due to easy access and for first aid	Seek care from private clinics	Private clinics offer services	Role of community health actors
There are times when you give birth to a child and he develops what they call 'bidama' in lusoga, you have to take the child for traditional intervention.	Local / traditional disease s are treated at traditional healers	Traditional illness requires traditional treatment	Care from traditional sector	Role of community health actors
At Musawo Monica's clinic in the trading centre and that is where she was immunized from because they send vaccines from Magada every end of the month.	Mothers are aware and immunize children at outreaches	Private clinics used for immunization outreaches	Public – private partnership	Role of community health actors
When the body changes and becomes yellow, child has a problem..., if the baby has been breastfeeding well, the feeding pattern reduces or it cannot suckle	Baby has a problem when he turns yellow,...if he reduces or stops breastfeeding	Yellowing, failure to breastfeed show baby is unwell	Knowledge of danger sign	Caregiver knowledge,
Sometimes if the past experience from Nakavule (Hospital) was very bad so you are forced to go to clinics.	Go to clinics due to bad experience at hospital	Bad experience at hospital	Past experience at health facility	Caregiver experience
When you are a husband at home, yet you don't have money, the one who has money decides.	The one who has money is the one who decides	Decision depends on availability of money	Both mother and father can decide	Decision making autonomy

3.5.2 Study II

Data were checked for completeness, entered in Epi- data software and exported to STATA version 10 for descriptive statistics. Due to the small number of CHWs involved in the study, summary measures used were median and interquartile range (IQR) and statistical comparisons between groups were made using a non- parametric test, the Wilcoxon rank-sum test (Wilcoxon et al. 1970).

The following computations were done and reported:

i)   Proportion of CHWs who attained the predetermined pass mark for each attribute. The pass mark for knowledge was 100%, for identification of sick newborns, and 90% for effective communication.

ii) Comparisons were done between Iganga and Mayuge districts for the CHWs in regard to the three attributes.

3.5.3 Study III

Data were checked for completeness and double entry was done to reduce data entry errors using Epi-Data statistical software. Double entry of data is considered a gold standard of good clinical practice (Ohmann et al. 2011). Data were exported to STATA version 10 for analysis. Univariate statistics were used to describe the characteristics of the newborns and their care takers. The proportion of caretakers who complied with the newborn referral was calculated, using all newborns enrolled in this study as the denominator. Referral compliance was defined as a health facility visit by the newborn caretaker within the 24 hours following a CHW's assessment of a newborn and issue of a referral form. A 24 hour period has been used previously by other researchers (Kallander et al. 2006; Darmstadt et al. 2010b) Caretakers who reported to health facilities after 24 hours or did not report at all were considered non-compliant.

To classify the socio-economic status (SES) of households, principal component analysis (PCA) was run on 12 selected household assets. The principal component on which most assets loaded was used to generate an SES score for each newborn's household. The households were then grouped into five descending SES quintiles, with a higher quintile indicating higher SES. This method has been used in a study conducted in the same setting by Mayega et al., (Mayega et al. 2012) and in the Uganda Demographic and Health Survey (UBOS 2012)

In order to identify factors associated with compliance with newborn referral, multi-variable logistic regression analysis was used, with timely newborn referral compliance as the binary outcome. Prior to conducting multivariable analysis, multiple co-linearity was investigated by using the correlation coefficient between each pair of the independent variables. Where two variables were found to have a correlation coefficient value greater than 0.5 with a p-value of less than or equal to 0.05, one of them was excluded in the analysis, retaining the one with a higher p-value in the model. A final model was obtained containing only variables with a p-value less or equal to 0.05.

3.5.4 Study IV

All the data were checked for completeness and double entered in the computer using EPI Data software and exported to STATA version 10 for analysis. Proportions were calculated for different items (equipment, supplies, drugs) in health facilities and for offering delivery and newborn care services. Mean availability index and scores and were computed using the Service Availability and Readiness Assessment (SARA) method, developed by WHO for measuring health systems readiness in service delivery (WHO 2012b). Mean availability score for indicator is computed as; Sum of items present in facilities per indicator divided by the product of items per indicator and number of health facilities, multiplied by 100%. The Mean availability index is the Mean of mean availability score for the indicators.

The proportion of health workers who had trained in newborn care, those who had received supervision and those who were knowledgeable (who attained the predetermined pass mark of 80%) about newborn care were also calculated. The overall median score and individual median scores for each of the three knowledge areas of preterm/low birth weight, birth asphyxia and infection were also determined.

Further, differences in health workers' knowledge by facility ownership (public/private) were examined. The proportion of health workers skilled in newborn resuscitation was computed and stratified by the characteristics of health worker cadre and facility type. For all the analyses, the differences between groups were tested using Fisher's exact test and the level of significance was considered at <0.05.

3.6   ETHICAL CONSIDERATIONS

All the studies were approved by the Higher Degrees, Research and Ethics Committee (HDREC) of the School of Public Health at Makerere University College of Health Sciences in 2011 and subsequently obtained a final approval certificate (reference number SS2660) from the Uganda National Council of Science and Technology (UNCST). In all the studies, the participants gave written consent prior to their participation. The research team members explained the purpose of the studies to all the study participants and emphasized that enrollment into the study was purely voluntary. Participants were at liberty to cease participation at any time without any penalties.

In the qualitative study (Study I) we sought consent to use recorders and individual written consent from both focus group discussions (FGD) and in-depth interview (IDI) participants. Illiterate participants consented by using thumb prints. Only participants aged 18 years and above were recruited for interviews and discussions.

To ensure confidentiality in studies II and III, questionnaires were labeled using identification numbers only. Similarly, FGD and IDI participants (Study I) were assigned identification numbers during the discussions and transcription, such as FGD-000 and IDI-000, where the first digit represented the type of FGD (for example, male or female), the second digit represented the district and third digit the serial number of the FGD. In addition, all files and code books were password protected and kept by the principle investigator.

In all the studies, no money or incentives of any kind were offered to the study participants. However, a soft drink was offered to each participant during the FDGs (Study I). In study (I), one of the risks of participation was mothers leaving their babies at home to take part in the discussions; this was minimized by allowing the mothers to come with their babies and also by limiting the discussions to not more than one hour. In Study (III), children found to be sick during the survey were referred to the nearest health facility for care.

4 RESULTS

4.1 SOCIO-CULTURAL FACTORS AFFECTING COMPLIANCE TO COMMUNITY NEWBORN REFERRALS (I)

The socio-cultural factors found to affect compliance to community newborn referrals were grouped into three sub-themes, namely community understanding of the newborn period and cultural expectations; the community health actors; and caregiver knowledge, experience and decision-making autonomy.

4.1.1 Community understanding of the newborn period and cultural expectations

Community understanding of newborn period

There was a term for a newborn, '*Nakaghwele*', and a newly delivered mother '*omwibo*', but there was no common understanding of the newborn period. Participants expressed their own understanding of the newborn period as one ranging from a week to two years. One male FGD participant explained: *"Nakaghwele starts at one day up to six weeks"* while another one mentioned, *"it is when you have just delivered up to three month.* A female FGD participant mentioned,*"a newborn stops at six months...",* while another mother said,*"for me a newborn is when it reaches two years..."*

Furthermore, the participants described the newborn period in relation to different time points such as commencement of supplementary feeding, attainment of specific growth milestones, such as starting to walk or crawl, and the ability to care for itself. However, the most common marker to end the newborn period was umbilical cord detachment as emphasized by a participant in the men's FGD,*"... It is our cultural practice, as long as the cord gets off; it ceases to be called a newborn."* Most participants agreed that the cord dropped off within a week after delivery. In addition, participants believed that during the newborn period, the child was delicate, vulnerable to diseases and the environment, and need to be protected and cared for in a special way.

Seclusion period

The need to protect the newborn due to its vulnerability to diseases and the new environment was expressed by the norm of keeping the mother and newborn exclusively indoors until the umbilical cord dropped off. This seclusion period is locally known as a*kisanda* and is believed to last about seven days. Mothers were expected to strictly observe this seclusion period irrespective of their place of delivery. The participants seemed to strongly believe in the seclusion period, but at the same time were flexible in cases when the baby was unwell. A participant in a men's FGD asserted, *"A baby with an umbilical cord does not come out of the house and doesn't cross the road unless when sick".*

The seclusion period was believed to protect the baby from harm that might be caused by coldness, contagious diseases such as measles, and evil spirits that were deemed to be in the wind. The seclusion practice did not discriminate between boys or girls as one mother reported during the interview, "w*hether a boy or a girl, they are not taken out so long as the umbilical cord is not yet off."*

4.1.2 Community health actors

Several health care providers existed in the communities, including CHWs, TBAs, and herbalists, private care providers operating clinics and drug shops, and the formal health workers. These health actors played different roles in the provision of maternal and newborn care including compliance to community newborn referrals.

Community health workers
The linkage between health facilities and communities was strengthened by the presence of CHWs who frequently interacted with the mothers and promoted recommended maternal and newborn practices, and also facilitated newborn referrals to the formal sector, as elaborated by a participant in the women's FGD: *"for the newborn, we have people who come to the community and educate us when we are pregnant so when I recognize that the child is not well, I take the child to the community health worker and after the CHW has seen the child she may advise me to take the child to the health facility and I take it either to Busowobi, Busesa or Iganga (health facilities)."*

Traditional health practitioners
Although the primary role of the TBAs was to assist mothers with delivery, they occasionally facilitated referrals of mothers identified to be at risk of maternal complications to the health facilities. Meanwhile, other traditionalists were entrusted to care for patients with symptoms such as convulsions, which are believed to be treated by traditional practitioners. A mother engaged in an in-depth interview explained: *"when the newborn convulses most people in this community take their children for traditional treatment"*.

Private clinics and drug shops
Private clinics and drug shops were described as easy to access in times of need for health care, since they are located near the community members. They were also viewed as sources of first aid in case the children were sick. Depending on the perceived severity of the child's illness, parents reported seeking care from these facilities prior to going to the formal health facilities. A female FGD participant narrated that, "w*e go there because clinics are near and easy to access. And still it depends on the baby's situation; you may just go and get first aid from clinics before you proceed to the hospital"*.

Private/Public health facility collaboration
Apart from providing services such as sale of drugs and administration of treatments to patients, some private clinics provided venues from which health workers conducted outreach services such as immunization. The community members were aware of such collaborations and utilized the services. A mother who did not comply with the CHW's referral advice revealed that she waited for the outreach services in her community to immunize the newborn. She explained that, "…a*t the clinic in the trading centre, is where she [the baby] was immunized because they send vaccines from Magada [a public health facility] every end of the month."*

4.1.3 Caregiver knowledge, experience and decision-making autonomy

Knowledge of signs that indicate severe illness, previous interactions with the health system, and perceptions of poor quality of care at the health facilities by the participants emerged as important facilitators and barriers to newborn referral compliance. Study participants expressed willingness to comply with referral advice and seek care if the newborns were unwell. However, rude health workers, lack of supplies and medicines, and experiences they described

as 'bad', deterred them from seeking referral care at the health facilities as advised by the CHWs, and instead they went to private clinics. One man complained: "*sometimes if the past experience from Nakavule (Hospital) was very bad you are forced to go to clinics.*"

Box 1: Summary of key findings

There is a discrepancy between the community's understanding of the newborn period and the biomedical definition. While the biomedical workers define it as the first 28 days of life, the community perceives it to last for various periods of time, sometimes up to two years. There is a common belief in a seclusion period immediately after birth until the umbilical cord of newborn drops off, although this is changing, especially in the peri-urban settings. Several health actors in the communities play different roles which influence caretakers and compliance with referrals. These include CHWs, traditional health care providers such as TBAs, private clinics and drug shops, and the formal public and private health facilities. Many of the community's perceived newborn dangers were in agreement with biomedical ones, although a few were not. The community members who mentioned the danger signs were inclined to complying with the referrals. Perceived weaknesses of the health system such as rudeness of health workers, absenteeism, or stock outs of medicines and supplies, may act as barriers to compliance with referrals. Perceived strengths of the health system, like the trained health

After exploring the community beliefs and practices that would affect caretakers compliance to referrals during the newborn period, the next step was determine whether lay persons trained as CHWs could identify and refer sick newborns for health facility based care.

4.2 IDENTIFICATION AND REFERAL OF SICK NEWBORNS AND THOSE FOR POSTNATAL CARE BY COMMUNITY HEALTH WORKERS (II)

Out of the 57 CHWs evaluated, the majority were females (50 out of 57, 70%) and 49 (86%) had completed over 7 years of formal education. To assess whether the CHWs could identify and refer sick newborns, they were evaluated for knowledge and recognition of newborn danger signs and the ability to effectively communicate to mothers of newborns.

Knowledge of newborn danger signs

The CHWs were tasked to mention at least five newborn danger signs unprompted, and 42 (74%) successfully did so. All of the CHWs mentioned red umbilicus or a cord with pus as a danger sign. CHWs were also prompted to identify 11 newborn danger signs and almost all of them (56 or 98%) correctly identified all the signs. Sixty eight percent obtained a predetermined pass mark of 100%. The knowledge median score was 100% (IQR 94%, 100%).

Recognition of newborn danger signs

Using four case vignettes, CHWs were asked to identify sick and health newborns, newborn danger signs and the action to take for the sick newborns. Fifty six of the CHWs (98%) correctly classified the four newborn case vignettes as either sick or not sick. All the CHWs (100%) correctly described the appropriate action to take for the sick newborns, which was referral of the sick newborn to the health facility. 'Preterm birth' was the least indentified danger sign from the case vignettes by only 29/57(51%) (Table7). Overall, 36 (63%) of the CHWs scored the predetermined pass mark of 90%. The median scores by the CHWs differed significantly between their district of work (Iganga= 91%, Mayuge= 82%), p<0.001.

Effective communication

Only 14 of the CHWs (25%) demonstrated all the required 10 communication attributes during the role-plays. The best performed attribute of communication was that of referring the baby after discovering that the baby in the role-play had a danger sign, demonstrated by all the CHWs (100%). Sixty percent of the CHWs attained the predetermined pass mark of 90%. The median score was 94% (IQR 89% -94%). The median scores differed significantly by the CHWs' district of work (94% -Iganga and 83% -Mayuge), p=0.001

Box 2: Summary of key findings

The majority of the CHWs (74%) were able to mention at least five newborn danger signs unprompted. Nearly all (98%) of the CHWs correctly classified the four newborn case vignettes as either sick or not sick. All the CHWs (100%) were able to correctly describe the appropriate action to take for the sick newborns which was referral to the health facility. 'Preterm birth' was the least identified danger sign by (51%) CHWs. Over two thirds (63%) of the CHWs were considered skilled in identifying sick newborns. A quarter of the CHWs (25%) demonstrated all of the required ten communication attributes during the role-plays, and a third of the CHWs (60%) were rated as having communicated effectively with the mothers.

Table 7: Community Health Workers who correctly identified case vignettes and newborn danger signs.

Newborn Danger sign	CHWs correctly identifying case as sick or not n (%)	CHWs correctly identifying specific danger sign in case scenario n (%)	CHWs recommending correct action for the newborn n (%)
Case Vignette 1- Sick Failure to suckle Smelly fluid oozing out of cord Skin pustules	57 (100%)	 42 (74%) 57 (100%) 54 (95%)	57 (100%)
Case Vignette 2- Not sick	53 (93 %)	***	51(89%)
Case vignette 3- Sick Feeling hot Baby's neck and limb stiff Very pale Preterm birth	57(100%)	 34 (60%) 36 (63%) 35 (61%) 29 (51%)	57(100%)
Case vignette 4- Sick No power in the limbs Difficulty in breathing Feels cold	56 (98%)	 52 (91%) 50 (88%) 47 (83%)	57(100%)

Having established that trained and regularly supervised CHWs are able to identify and refer newborns for treatment and postnatal care, it was necessary to establish barriers and facilitators of caretakers' compliance with referral advice given by CHWs.

4.2 COMPLIANCE WITH REFERRAL ADVICE BY CARETAKERS (III)

Newborn referral compliance
Over one half (373 out of 700, 53%) of the newborns were referred for immunization and postnatal care, and 47% were referred due to sickness. Overall completion of referral, irrespective of the time frame to seek care, was 640/700 (91%). Over two thirds (439, 63%) of the caretakers reported that they complied and sought referral care within 24 hours. The median time was 13 hours (range: 2 to 17 hours). More caretakers of sick newborns (243/327, 74%), complied within 24 hours compared to those referred for immunization and postnatal care (196/373, 53%, p<0.001).

Care for referred newborns
Of the 640 caretakers who sought referral care, 493 (77%) went to public health centres, 115 (18%) to hospital, and 32 (5%) to other facilities. Out of the 640 caretakers, 292 (46%) sought referral care because the baby was sick. Majority108/292 (37%) of the sick newborns were taken to Health Centre IIs (Figure 13).

Of the 39 sick newborns whose caretakers did not seek referral care at all were mainly treated at home (27, 68%). The caretakers treated these sick newborns either with medicines that they newly bought (21, 54%) or with old drugs stocked at home (6, 15%).
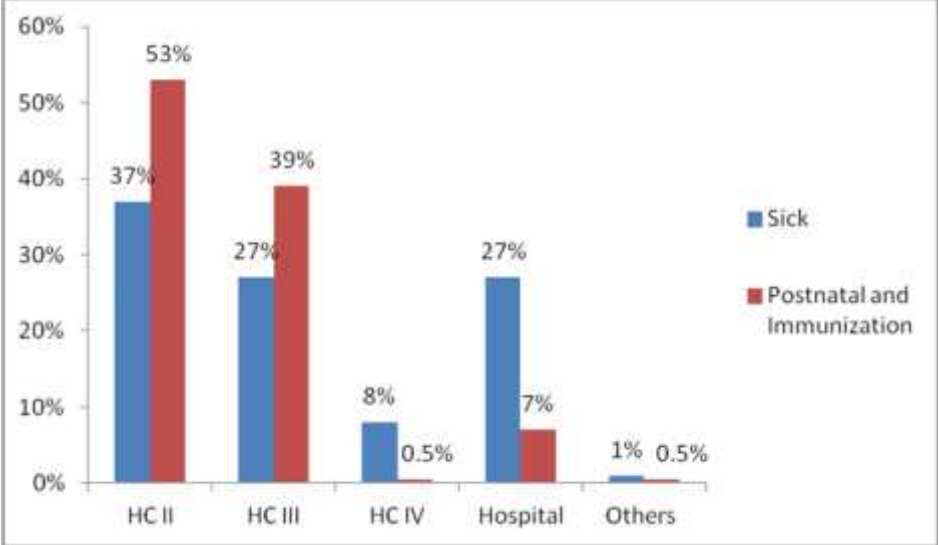
Figure 13: Type of health facility where caretakers of sick and healthy newborns sought care.

Reasons for noncompliance

A total of 261 caretakers did not comply; that is, they did not seek referral care within 24 hours or at all, as advised by the CHWs. The most common reasons mentioned for non-compliance included "the mother was sick/unwell" (50, 19%), "waiting for an immunization outreach" services in their area (45, 17%), and 39 (15%) were "waiting for the newborn's umbilical cord to drop off". The rest of the reasons are presented in Table 8.

Table 8: Barriers for timely compliance reported by caretakers of referred newborns.

Reason for non-compliance (Multiple responses allowed)	Overall N=261 Freq (%)
Mother sick	50 (19.2)
Waiting for immunization outreach	45 (17.2)
Waiting for cord to drop off	39 (14.9)
Lack of transport	22 (8.4)
Health workers absent during weekend	10 (3.8)
CHW advised mother to go after 1 week	7 (2.7)
Bad weather	5 (1.9)
Mother busy with work at home	5 (1.9)
Long distance to facility	3 (1.2)
Had sick person at home	3 (1.2)
Needed permission from husband	3 (1.2)
Other	16 (9.0)

Factors associated with newborn referral compliance

Age of the mother, reason for referral of the newborn, and a reminder visit by CHW within 24 hours were the factors significantly associated with compliance with the referral advice given by CHWs. Mothers aged 25 to 29 and 30 to 34 years were both 0.4 times less likely to comply with newborn referral advice compared to younger mothers aged 15- 19 years (AOR= 0.4, [95% CI= 0.2 - 0.8] and AOR= 0.4, [95% CI= 0.2 - 0.8] respectively). Caretakers whose newborns were referred because they were sick were 2.6 times more likely to comply with the referral advice compared to those who were referred for immunization and postnatal care, with an AOR 2.6 (95% CI=1.9 –3.6). Caretakers who received a reminder visit by the CHW within 24 hours following the initial referral were more likely to comply with the referral advice compared to those who did not receive such a visit (AOR 1.8, [95% CI=1.2 – 2.5]) (Table 9).

Table 9: Factors associated with timely compliance by selected caretaker and newborn characteristics.

Characteristic	Category	n-	# Complying within 24 hrs (%)	Crude OR [95%CI]	Adjusted OR [95% CI]
Age of mother	<20	53	12 (22.6)	1.0	
	20 - 24	178	58 (32.6)	0.6 [0.3 - 1.2]	0.6 [0.3 - 1.3]
	25 - 29	153	66 (43.1)	0.4 [0.2 - 0.8]	0.4 [0.2 - 0.8]*
	30 - 34	141	59 (41.8)	0.4 [0.2 - 0.8]	0.4 [0.2 - 0.8]*
	35 - 39	55	20 (36.4)	0.5 [0.2 - 1.2]	0.5 [0.2 - 1.3]
	40	35	13 (37.1)	0.5 [0.2 - 1.3]	0.4 [0.1 - 1.2]
Reason for referral of newborn	Immunization	373	196 (52.6)	1.0	
	Sick	327	243 (74.3)	2.6 [1.9 -3.6]	2.3 [1.6 - 3.5]*
Age of newborn at referral	<1week	607	233 (38.4)	1.0	
	>1 week	93	28 (30.1)	1.4 [0.9 - 2.3]	1.4 [0.8 - 2.5]
Reminder visit by CHW	No	153	78 (51.0)	1.0	
	Yes	533	353 (66.2)	1.9 [1.3 - 2.7]	1.7 [1.2 - 2.7]*

After examining the caretakers compliance and its determinants, there was need to assess the readiness of the health facilities, mainly first level ones, to offer care to newborns, focusing on the major causes of newborn deaths, namely, complications related to preterm, low birth weight and infections.

4.3   CAPACITY OF HEALTH FACILITIES TO CARE FOR NEWBORNS (IV)

Availability of newborn care inputs for preterm and low birth weight, asphyxia and infection services.

A total of 20 health facilities were assessed: 12 at level II, six at level III, one at level IV and one general hospital, of which the majority (15, 75%) were public and government-run (public) and five were private not for profit (PNFP). Indicators that were used to assess the capacity of health facilities to care for newborns were those of the main causes of newborn deaths: preterm/ low birth-weight, asphyxia and infections.

None of the level II facilities offered kangaroo mother care (KMC) services for preterm/low birth weight, while the availability score for this service was 67% for level III and 100% for the hospital/level IV. First level facilities (HC II) had the lowest availability score for resuscitation equipment compared to the hospital/level IV and those at level III (31%, 71% and74%). The availability score for newborn sepsis drugs was 8% for level II, and 67% and 75% for level III and the hospital/level IV.

Knowledge of newborn care by health workers

Of the 50 health workers assessed, 33 (66%) scored above a predetermined pass mark of 80%. The knowledge median score was 84% (IQR 77%, 88%). 'Infection' was the most known and 'preterm complications/low birth weight' the least known newborn areas, with 42 (84%) and 23 (46%) health workers scoring above 80%, in each area, respectively. Overall, a higher proportion of health workers from public health facilities (26/34, 76%) scored the pass mark of 80% or more than those from private not for profit (PNFPs) facilities (7/16, 44%, p-value = 0.03) (Table 10).

Table 10: Health workers with good knowledge of newborn care by ownership of health

facilities.

Newborn care component	Median percentage knowledge score (IQR)	Health workers who scored 80% n(%)	Facility ownership (Health workers)		
			Public (N=34) Scored 80% n (%)	*PNFP (N=16) Scored 80% n(%)	P value
Overall	84 (77, 88)	33 (66%)	26(76)	7(44)	0.03
Preterm	78 (74, 86)	23 (46%)	17 (50)	6 (38)	0.41
Asphyxia	86 (73, 91)	31 (62%)	24 (71)	7 (44)	0.07
Infection	92 (84,95)	42 (84%)	30 (88)	12 (75)	0.23

*PNFP: Private not for profit

Training and supervision of health workers on newborn care

Out of the 50 health workers, 42 (84%) reported having received training in at least one of the following newborn care components within one year prior to this study: newborn resuscitation using ambu-bag; early and exclusive breastfeeding; newborn infection management (including injectable antibiotics); sterile cord cutting and appropriate cord care; thermal care (including immediate drying and skin-to-skin care); KMC for low birth weight babies; special delivery care practices for preventing mother-to-child transmission of HIV;, use of corticosteroids for preterm labour; goal-oriented antenatal care; essential newborn care; or partographs. Out of the 50 health workers, 41 (82%) had received support supervision within the three months prior to the study. Twenty-one (42 %) of health workers received supervision from their seniors within the health facility, and had been observed as they provided newborn care. Sixteen (32%) had been directly observed by supervisors from district and national level as they offered newborn care.

Newborn resuscitation skills

Of the 42 health workers assessed for newborn resuscitation skill, 20 (48%) were midwives and an equal proportion worked in the hospital. The median skill score was 12/23 (IQR 5, 16). Seventeen (40%) were considered skilled in newborn resuscitation and out of these, a majority (11, 65%) worked in the hospital. Equal proportions of nurses and midwifes (8/17, 47%) were considered skilled. There were no significant differences among the skilled health workers by cadre or health facility type.

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Box 4. Summary of key findings

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HCIIs were least prepared to care for newborns. HCIIs had the lowest (31%) availability score for resuscitation equipment, compared to hospital/level IV (71%) and HC III (74%). HCIIs also had the lowest (8%) availability score for newborn sepsis drugs, in comparison with HC III (67%) and hospital/ level IV (75%). None of the HCIIs offered Kangaroo Mother Care for preterm and low birth weight babies. More than two thirds (66%) of the health workers were considered knowledgeable and 40% skilled in newborn care. 'Preterm complications/low birth weight' was the least known newborn area by the health workers.

5 DISCUSSION

5.1 MAIN FINDINGS

This thesis is one of the first studies to report high compliance with CHW newborn referrals and associated factors in SSA. Over 70% of the caretakers of sick newborns complied with the referrals (III). The factors associated with referral compliance were: being a young mother (<20 years of age), a baby being sick, and a caretaker receiving a reminder visit from a CHW (III). Trained community health workers were competent in identifying and referring sick newborns to health facilities (II) who were mainly taken to first-level facilities for care (III). However, these lower level facilities did not have adequate capacity to care for sick newborns (IV). Despite the common practice of seclusion in the neonatal period, CHWs were able to influence caretakers to seek referral care during this period, especially if the newborn illness was perceived as severe.

5.2 RECOGNITION OF ILLNESS AND DECISION TO SEEK REFERRAL CARE FOR NEWBORNS (DELAY 1)

Confinement of mother and newborn after birth

From the findings, there are cultural practices that are believed to prevent a newborn from suffering harm or contracting a disease (I), but instead these norms increase the risk of ill health for newborns. A confinement period culturally prescribed to mothers and the newborns, from immediately after birth until the baby's umbilical cord drops off, is meant to achieve protection by preventing the baby from being harmed by evil spirits or contracting diseases from family members and visitors. Several studies have described a similar period, observed for the same reasons, in addition to perceiving the mother as unclean and isolating her from the rest of the family (Choudhry 1997; Winch et al. 2005; Dennis et al. 2007; Mrisho et al. 2008).

Such confinement and restrictions of the mother and newborn from free movement and interaction with family members may have implications on the mother's ability to recognize danger signs, if the newborn develops one, contributing to the first delay. Often, the confinement rooms are poorly lit, which reduces the visual ability of the mother to spot danger signs (Kumar et al. 2009). Seclusion also puts the mother in an uncertain situation of whether to comply with referral advice and seek care for the newborn or stay in confinement for fear of the cultural consequences. However, in this setting where the UNEST intervention was ongoing, the CHWs assisted caretakers to recognize sick babies, counseled them to overcome the stigma of breaking seclusion and seek care for the newborns (II, III).

Cultural beliefs and risk of newborn death

The seclusion period coincided with the most risky time of the newborn's life, the first week after delivery (I), during which over 75% of newborn deaths occur (Lawn et al. 2005). This confinement potentially increases the risk of death for sick newborns if appropriate care is not sought. The belief that a newborn is a 'grown up' after the detachment of the umbilical cord may also affect the way the newborns are cared for and expose them to harmful practices, such as poor thermal care (Kumar et al. 2009), and eventually to undesired outcomes. This calls for program mangers to emphasize to caretakers the recommended newborn practices for the first month of life.

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Community Health Workers contribute to reducing Delay 1.
In this thesis, CHWs were found to play an important role in encouraging caretakers to seek care for the newborns by reducing Delay 1. First, the CHWs were found competent in identifying the newborns with danger signs that required treatment and those that were born outside the health facilities and needed postnatal care and referred them accordingly (II). A similar finding was reported in Zambia, where trained TBAs, who were working as CHWs, were able to identify, treat and refer sick newborns (Gill et al. 2014). However, the CHWs in this thesis had challenges with indentifying preterm and low birth-weight as a danger sign (II).

Furthermore, the findings demonstrated that, when a CHW made a reminder visit to the household within a day after the original counseling, the caretaker was more likely to make a decision and seek referral care than when such a visit did not happen (III). It is possible that the caretakers viewed reminder visits as a sign of emphasis that the baby needed to be taken for referral care. To our knowledge, no study has reported this evidence before. This finding calls for emphasis during CHW trainings about the importance of reminder visits in motivating caretakers to comply with referrals.

5.3 REACHING HEALTH FACILITIES FOR NEWBORN CARE (DELAY 2)

High compliance with community health workers' referral advice
In this thesis, seven in ten of the caretakers of sick newborns complied with the referral advice within 24-hours. An overall completion rate of 91%, irrespective of time to completion, was also observed and was similar to the 84 to 95% documented in Ghana, South Africa, and Zambia (Kirkwood et al. 2013; Nsibande et al. 2013; Gill et al. 2014). In south Asia, the level of compliance ranged from 34 to 54% (Baqui et al. 2008; Darmstadt et al. 2010b). The high compliance observed in this thesis could be attributed to short distances to the health facilities, since the majority of the caretakers walked to seek referral care (III). Proximity to health facilities has been known to contribute towards referral completion (Atkinson et al. 1999). Similarly, in the South Africa study, the majority of the participants also walked to seek care (Nsibande et al. 2013). Secondly, since this study was in the context of the UNEST intervention, the reminder visits made by the CHWs after initiating the referrals (III) could have demonstrated to the caretakers the need to act and seek care, resulting into the high compliance. It is also possible that the facility-community linkage and health system strengthening done by UNEST created confidence among the community members to seek care from health facilities.

Caretakers of sick newborns mainly sought care from the lower public health facilities (III). Lower level facilities are closest to the communities and serve as the first contact to the health system (IV), so caretakers might have found it convenient to seek care from these facilities. Secondly, previous studies have shown that caretakers of newborns are unlikely to seek care from higher level facilities due to various barriers, such as transport costs (Peterson et al. 2004; Mbonye et al. 2012). A similar trend of seeking care from lower facilities rather than hospitals was also reported in the studies conducted in Ghana and South Africa (Kirkwood et al. 2013; Nsibande et al. 2013).The high compliance, coupled with the fact that caretakers sought care from the lower level facilities (III), is evidence that caretakers of newborns can reach the health facilities for care. The challenge is then for the health workers to provide quality services to the newborns. Provision of quality health services is one of the building blocks of a health system

that needs to be in place for the effective delivery of health services (WHO 2007). It is also the basis for the third delay in the healthcare seeking model, discussed further below (Thaddeus et al. 1994) .

Facilitators and barriers of compliance with referrals

This thesis highlights the factors associated with newborn referral compliance in SSA for the first time. The findings demonstrate that being a young mother (<20 years of age), the baby being sick at the time of referral, and caretakers receiving a reminder visit from the CHWs were the determinants for compliance with referrals. The young mothers being more likely to seek referral care than the older mothers was a surprising result, since available evidence shows that the former, are vulnerable, and many times find it challenging to seek care (Atuyambe et al. 2009). Possibly, the young mothers in our study were able to seek care because the majority of them were married (III) and might have received support from their spouses; Atuyambe et al., found that married young mothers were more likely to seek health care because of the support from their partners (Atuyambe et al. 2008). Secondly, the majority of the sick newborns (54%) were born to young mothers (III), and sickness was a predictor for compliance (III). In addition, many young mothers were also first-time mothers (III), most likely without other children to care for, compared to older mothers who may have more than one child. In this study, one of the reasons mentioned for noncompliance was taking care of another sick person in the home'. Although the birth order of the baby was not significantly associated with compliance, the older mother could have been reluctant to seek care given their previous experience in parenting newborns, compared to the young ones.

 Several barriers were identified that deterred caretakers from complying with referral advice. The most commonly mentioned reasons for noncompliance were: 'the mother felt unwell at the time when the CHW pronounced the referral', 'waiting for outreach' and 'waiting for the umbilical cord to detach' (III). The mothers' poor health status could have been a result of the possible complications that can occur during birth and/or after delivery. Such morbidity is likely to still exist in the first week after delivery. Glazener et al., reported that almost 9 in 10 of mothers reported health problems after delivery (Glazener et al. 1995). So, if the CHWs conducted home visits and initiated referrals during the first week, when women may have been likely to be ill, it may have deterred compliance with the referrals. A mother's illness was also reported to be a barrier to compliance in Bangladesh (Bari et al. 2006).

Some of the newborns were presumably healthy, but were referred for postnatal care and immunization, since they were born outside the health facilities. Perceived severity of illness by the caretakers has been reported to influence compliance with referral (Simba et al. 2009). It is therefore not surprising that the caretakers of the newborns referred for postnatal care, that were assumed to be healthy, decided to wait for the immunization outreach services conducted within the communities, rather than comply with a referral within 24 hours. This implies that there is a low appreciation by caretakers for the benefits of postnatal care services. Alternatively, it could be an issue of a lack of money for transport, and that the caretakers choose to wait for the services nearby. Travel costs have been shown to be one of the barriers to completion of referrals for sick infants in Ecuador and Uganda (Kalter et al. 2003; Peterson et al. 2004).

The finding that caretakers did not comply with referral advice because they were waiting for the umbilical cord to drop off was in line with the cultural practice of keeping the mother and newborn exclusively indoors until the umbilical cord detached (I). Similar cultural beliefs were reported to influence care-seeking for newborns in Bangladesh (Winch et al. 2005). This finding suggests that there is a need for interventions, for example CHWs, to assist caretakers to overcome such cultural issues.

Other barriers highlighted in this thesis include: poverty, the decision making processes, and health system weaknesses such as health worker absenteeism, drug stock outs, and poor quality of care (I, III). This could be attributed to the fact that the study context was predominantly rural where such issues are likely to prevail (Kiwanuka et al. 2008). These barriers have also been reported to contribute to noncompliance in seeking newborn care by other authors (Atkinson et al. 1999; Bari et al. 2006; Baqui et al. 2009b).

5.4 PROVISION OF QUALITY NEWBORN CARE IN HEALTH FACILITIES (DELAY 3)

Availability and competence of health workers
In most facilities, a skilled provider was stated on work schedules to be available 24 hours a day, including on weekends (IV). This was a good finding, showing that health worker absenteeism, especially over the weekend, may be partly solved, since it was one of the barriers mentioned by caretakers of newborns for noncompliance to CHW referrals (I). However, paper schedules may not be the reality. A study done in six countries, including Uganda, showed that almost four out of ten health workers at HCIIIs were absent from work, irrespective of the facility work schedule (Chaudhury et al. 2006).

Although health workers were found to be weakest in the assessed area of 'preterm', they were generally knowledgeable in newborn care (IV). This could be attributed to the trainings conducted by UNEST during their health system strengthening activities. However, the health workers' newborn resuscitation skills were unsatisfactory (IV). This could be due to lack of "hands on" supervision (IV) or decay in the skill, resulting from allocation of staff at services points where the resuscitation skill is not exploited (Vesel et al. 2013). For health facilities to provide quality referral care for the newborns, there must be knowledgeable and skilled staff (Simoes et al. 2003; Peterson et al. 2004). Competent human resources are a building block of an effective health system; inadequate skills among health workers compromises the quality of services offered to the newborns and in turn weakens uptake of services (I).

Newborn care services at lower health facilities
Many of the first level facilities (HCIIs) were reported to offer delivery services, although this is not their core duty. They were offering these services because they had been upgraded by the district authorities to meet the demands of the community members in their catchment areas (IV). However, newborn care services were not introduced along with the upgrades, and after delivery, the health workers are automatically exposed to newborns that may require newborn care such as resuscitation or preterm and low birth weight interventions like KMC. This needs to be addressed. Wherever deliveries are conducted, there needs to be preparedness for newborn care.

Medicines and technologies, is another building block that supports a health system in delivering health care. The HCII facilities were least equipped to offer care to the newborns for the major causes of newborn deaths: preterm/low birth weight complications, birth asphyxia and infections (IV). This discrepancy that, these facilities offered delivery services yet were least equipped to deal with newborn care, could be attributed to the existing policy that does not permit HC IIs to stock newborn sepsis drugs, coupled with the fact that normal delivery is not a designated service at this level of the health system (MOH 2010b; MOH 2012). Previous studies have also documented similar findings of health facilities in general not being adequately equipped to care for newborns in SSA (Nolan et al. 2001; Opondo et al. 2009; Nesbitt et al. 2013; Vesel et al. 2013). When the caretakers overcome individual and community barriers to reach health facilities, but instead do not receive the intended services, they may revert to self-medication, private sector care, or no care at all (I, III).

5.5 CONTEXTUALIZING FINDINGS TO IMPROVE NEWBORN SURVIVAL

The findings in this thesis have demonstrated that through the use of CHWs, the first and second delays can be addressed, but challenges remains with the third delay. The caretakers can be supported in recognizing sick newborns and motivated to make a decision to seek referral care, but the health facilities are not adequately prepared to offer quality care to the newborns. Therefore, to improve newborn outcomes, models have to be designed to deliver quality newborn services at the facility level in Uganda and in similar contextual settings.

One of the models would be to improve the capacity of the first level facilities (HCIIs) by providing them with the basic equipment, supplies and drugs that are necessary to offer care to newborns. This would call for a revision of the essential drug policy to allow HCIIs stock newborn sepsis drugs (injectable gentamycin and ampicillin). Secondly, it would also require training health workers in newborn resuscitation skills and supporting them through regular supervision. At the same time, the caretakers should be encouraged to seek newborn care through the existing VHT structure.

Another model is to borrow a page from studies that have demonstrated reduction in newborn mortality by using trained CHWs to treat and refer sick newborns at the community level instead (Bang et al. 1999; Bang et al. 2005; Baqui et al. 2008; Kirkwood et al. 2013). In SSA, Ethiopia has been able to reduce its child mortality using this strategy, from 205 deaths per 1000 live births in 1990 to 64 in 2013, making it one of the countries that has achieved her MDG-4 target of less than 68 deaths per 1000 live births. However, the rolling out of trained CHWs would still require improvement in the capacity of health facilities, because referring sick newborns to facilities that cannot offer quality care may not result into the desired reductions in newborn mortality, as was demonstrated in Ghana by Kirkwood et al.,(Kirkwood et al. 2013).

Yet another model is to provide innovative strategies to improve the referral system, from first level facilities to the higher levels where better newborn care is offered. This model would also require mitigating barriers to referral compliance such as the transport infrastructure and transportation charges reported by Peterson et al., (Peterson et al. 2004).

It should be noted that in Asia and Ethiopia, the first contact with the health system is at the hospital level, but this level is connected to the distant population with formally employed extension workers. On the other hand, Uganda operates a tiered system of facilities, from HCII, III, IV, district, regional to national hospitals, and 72% of its population lives within a 5 km radius of a health facility (MOH 2010b). Uganda could exploit the proximity of the health facilities to the populations and improve capacity of the first level facilities to care for the newborns from which the population mainly seeks care (III). Improving health facilities would be a triple investment as this could be used to control maternal mortality and stillbirths (Bhutta et al. 2014). However, for the successful delivery of services, cost and financing, another building block of the health system, must be consider while evaluating the model options. Costing was not part of the scope of this study.

6.0 METHODOLOGICAL CONSIDERATIONS

6.1 GENERALISABILITY AND TRANSFERABILITY OF FINDINGS

In research, the term generalisability refers to the ability to apply results of one study population to larger populations and other settings. Generalization of results depends on validity of the study. Validity refers to the extent to which a study measures what it intended to measure (Gordis 2009). Achieving both requires proper selection of study participants, a large enough sample size and adhering to the study protocols. In study(II), all the target study population (61 CHWs) were recruited, in study(III), a census of all the referred newborns was done and in study IV, all the UNEST intervention health facilities were include in the study. In all the studies, effort was taken to stick to the study protocols. However, all studies were conducted in one region, in an area that hosted a newborn intervention under the Uganda Newborn Study. Possibly, this means that the findings reflect a better situation than the typical one in Uganda. This may limit generalization of the findings necessitating studies in non intervention context.

In qualitative research, the term generalisability is not used, rather it is transferability. Transferability refers to the extent to which the findings can be transferred to other settings of groups (Graneheim and Lundman 2004). Graneheim and Lundman continue to state that "there is no single correct meaning or universal application of research finding, but only the most probable meaning from a particular perspective". In study (I), community members in various categories (geographical location, urban, rural, age, and sex) were recruited to generate a variety of opinions and lived experiences, using triangulated methods (FGDs and IDIs). Therefore these findings may apply to settings with similar context of low health care utilization and a weak health care system.

6.2 DEFINITION OF COMPLIANCE

Compliance to referral was defined as a caretaker visiting a health facility within 24-hours following a CHW's assessment of a newborn and issuing a referral form. Caretakers who reported to health facilities after 24-hours or did not report at all were considered non-compliant. A shorter response period after referral advice could have been considered given that newborns exhibiting danger signs require immediate care otherwise; 24-hour delay may result into death, majority of newborn deaths occur within first 24hours after delivery (Lawn et al. 2005; Malqvist et al. 2010). However, given that multiple factors including individual, household and health facility interplay to complete referral, a 24-hour period was deemed most realistic and has been used previously by other authors to define delay in compliance with referral advice (Kallander et al. 2006; Darmstadt et al. 2010b).

6.3 CASE VIGNETTES

Vignettes are simulations of real events which can be used in research studies to elicit subjects' knowledge, attitudes or opinions according to how they state they would behave in the hypothetical situation depicted (Flaskerud 1979). Ideally, the CHWs' ability to identify newborn danger signs should have been assessed using actual sick newborns. However, given that newborns with danger signs were not readily available, and that sick newborns need to be treated immediately to save their lives, use of case-vignettes was found most appropriate, although they may not have adequately depicted newborn danger signs as the real sick

newborns. Thus, it is possible that our finding may have been different with actual sick newborns, where by CHWs could have recognized the sick newborns better using their visual ability and clinical judgment. Gill et al., found that newborns deemed 'extremely sick' by referring TBAs, were nine times more likely to die than those judged less ill.

6.4 LIMITATION WITH SELF REPORTS

In study (III), information on compliance was elicited through self reports, that is, interviewing caretakers. Data collected though self reports are believed to be more subjective than that obtained by observations and measured practices (Schoeller 1995). However, participant self report method, was found to be plausibly accurate in obtaining medical utilization information in the previous year in an old study cohort (Lubeck et al. 2005). An attempt was made to verify if caretakers reached the health facilities after receiving referral advice, but due to the poor record keeping in health facilities in this setting, this task was not achieved. Instead self reports were used as in other studies (Peterson et al. 2004; Simba et al. 2009).

6.5 RECALL BIAS

In study (III) we conducted the assessment one and half years after the initial start of the intervention. This could have created recall bias making some information less accurate than it would have been, had it been collected immediately after the CHWs advised caretakers to seek referral care. In the effort to minimise recall bias some of the information was directly recorded from the referral forms. Therefore, the data was deemed reasonably accurate given that some of the critical variables for this study, such as newborn age at referral, date of referral, reason or sign and symptom at referral, were recorded from the duplicate referral forms kept by the CHWs.

6.6 REFLEXIVITY

Reflexivity refers to awareness of researcher's role and how its accounted for in the research process (Haynes 2012). The studies were conducted in an area where I was an outsider, with no prior interaction. When I participated in qualitative data collection, I was open to opinions of the study participants. However, as a health worker there might have been fear created on the side of the participants but this was minimized by the moderator of the discussions and interviews introducing me as a researcher from School of Public Health, Makerere University rather than as a medical personnel. I was also able to understand the discussions and cultural context, given that my ethnical background is similar to that of the Basoga, the predominant ethnical group, in the study area.

7. CONCLUSION AND RECOMMENDATIONS

7. 1 CONCLUSION

- There was a high compliance with CHW referrals, but caretakers sought care from first level facilities, which lacked the capacity to care for sick newborns (III, IV).

- Trained community health workers, when engaged in maternal-newborn programs, can assist caretakers to recognize sick newborns, change common practices like seclusion and achieve good referral care-seeking for newborns (I, II, III).

- Poor health status of the mother, poverty, decision making processes, community beliefs and understanding around the newborns, and health system weaknesses such as health worker absenteeism, were barriers to seeking care for newborns (I, III)

- Although CHWs and health workers had good knowledge about newborn care, they were both weakest in the preterm area. In addition, health workers had unsatisfactory skills for the resuscitation of newborns (II, IV).

- Community members understood the newborn period differently from the health workers (I)

7.2 RECOMMENDATIONS

- The Ministry of Health should provided basic equipment, supplies and medicines for newborn care to facilities that conduct deliveries, irrespective of their level of service, to address the main causes of newborn deaths: preterm and low birth weight complications, birth asphyxia and infections.

- The Ministry of Health should also consider revision of the policy that limits HCIIs from stocking newborn sepsis drugs to enable babies who require this treatment benefit from it.

- Existing structures like the village health teams, who are CHWs in the Ugandan context, could be utilized to assist caretakers to recognize newborn danger signs and also support them to make decisions and seek health care in a timely manner. The VHTs could also be engaged in maternal and newborn programs to assist caretakers in overcoming some of the social and cultural barriers to compliance with newborn referrals, while at the same time strengthening community-facility linkages

- Program managers need to explicitly define the target age group in all community newborn interventions to ensure that communities understand the group of children concerned, as well as address locally existing cultural beliefs that can affect utilization of newborn care.

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