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

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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.)

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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.

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
AOR	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
HDREC	Higher Degrees, Research and Ethics Committee
HDSS	Health Demographic Surveillance Site
IDI	In depth Interviews
IMCI	Integrated Management of Childhood Illnesses
IQR	Interquartile range
KI	Key Informants
KMC	Kangaroo Mother Care
MDGs	Millennium Development Goals
MOH	Ministry of Health
NDP	National Development Plan
NHP	National Health Policy
OR	Odds ratio
PCA	Principal Component Analysis
PHP	Private Health Practitioners
PNFP	Private Not for Profit
SARA	Service Availability and Readiness Assessment
SES	Social Economic Status
SNL	Save Newborn Lives
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
UNCST	Uganda National Council of Science and Technology
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 aged 0-28 days. 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 (23%) (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.
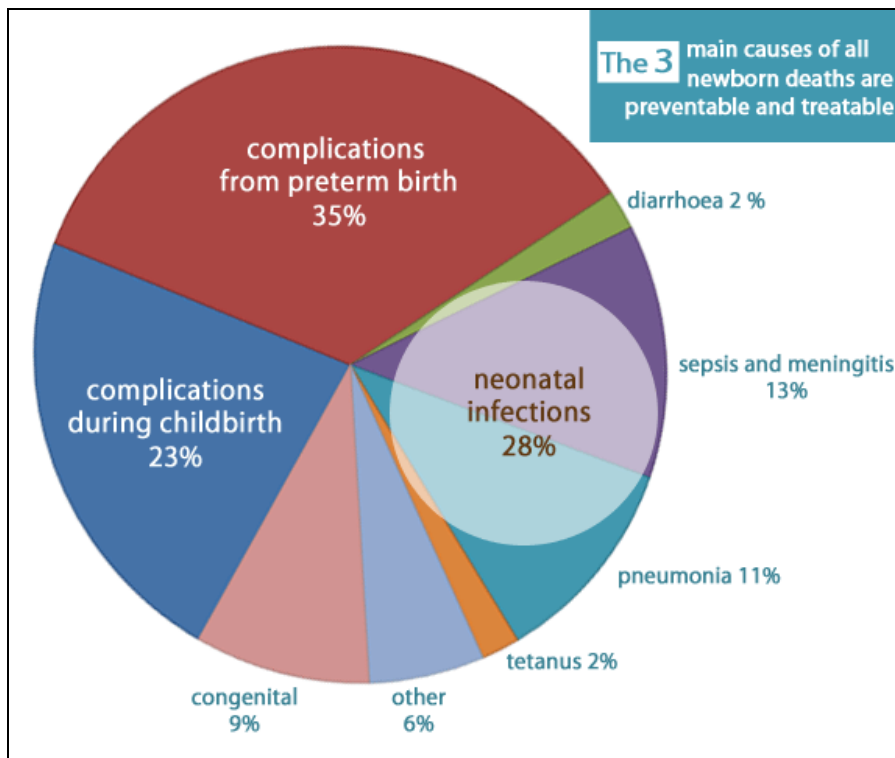
Figure 1: Causes of newborn deaths worldwide.
Source: Liu, L., H. L. Johnson, et al. (2012). "Global, regional, and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000." The Lancet 379(9832): 2151-2161.

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

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unmet need for family planning methods, high adolescent pregnancies and child marriages (Lawn et al. 2014).
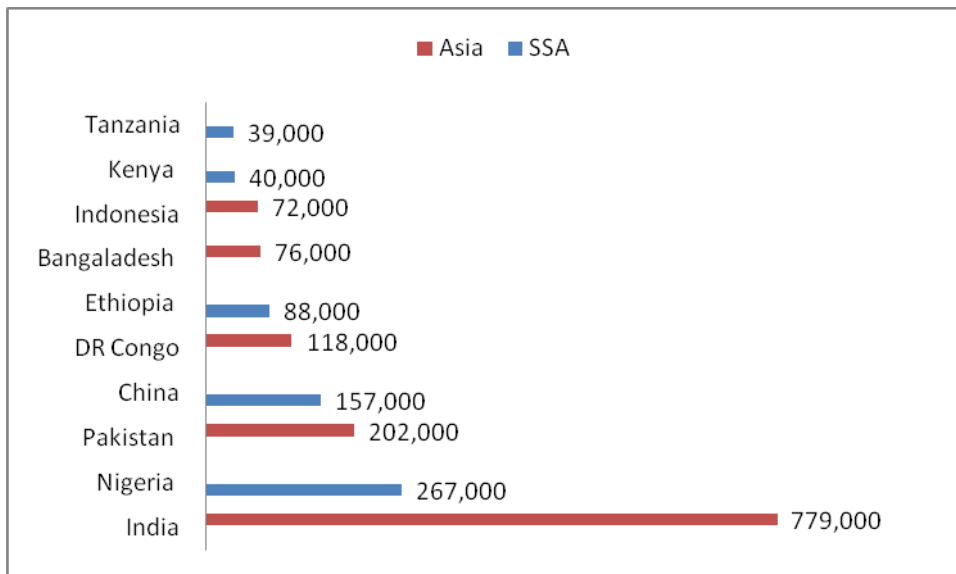

Figure 2: Top ten countries contributing to 60% of worldwide newborn deaths.
Source: Adapted from UNICEF, WHO, The world bank, UNFPA, 2013. Levels and Trends in Child mortality, report 2013

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 (Figure 3.)

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).

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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).
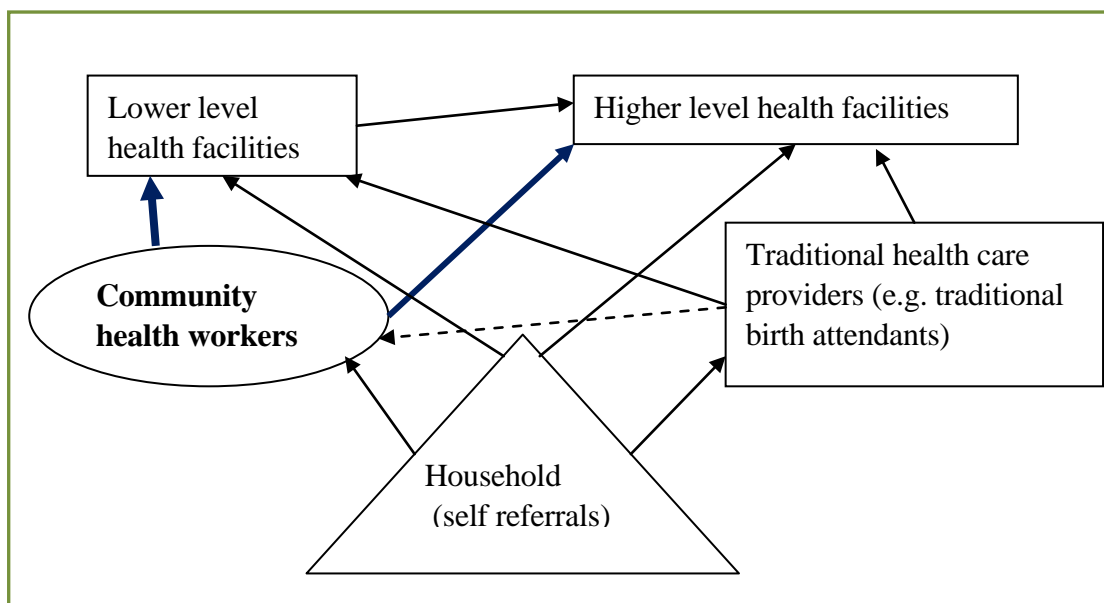
Figure 5: Newborn referrals by community health workers investigated in a study in this thesis shown by bold arrows.

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.

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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).

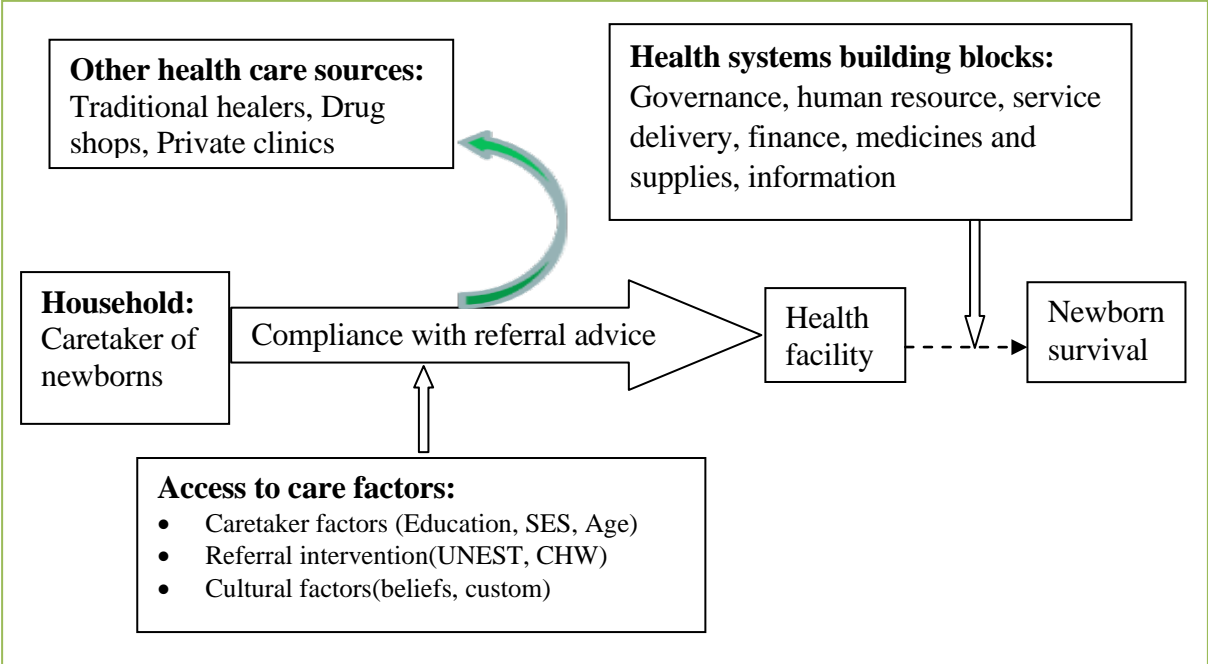
Figure 6: Access to newborn care and the health system

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 Department 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 (CSS) 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 efficacy*) (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 such as household income, community eg the cultural beliefs and health system factors like availability of competent health workers and logistics to offer quality care . 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.
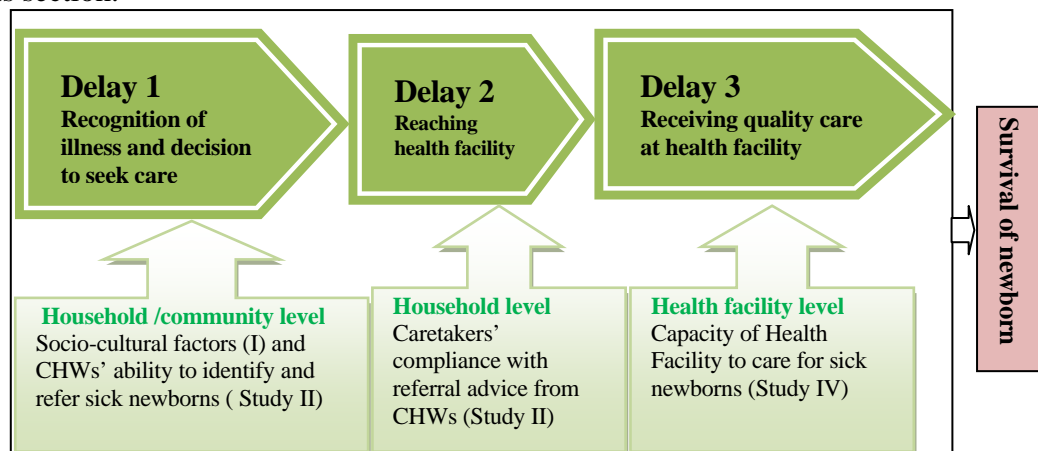

Figure 7: Conceptual framework for the thesis adapted from Thaddeus and Maine's Three Delays model (Thaddeus et al. 1994)

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).
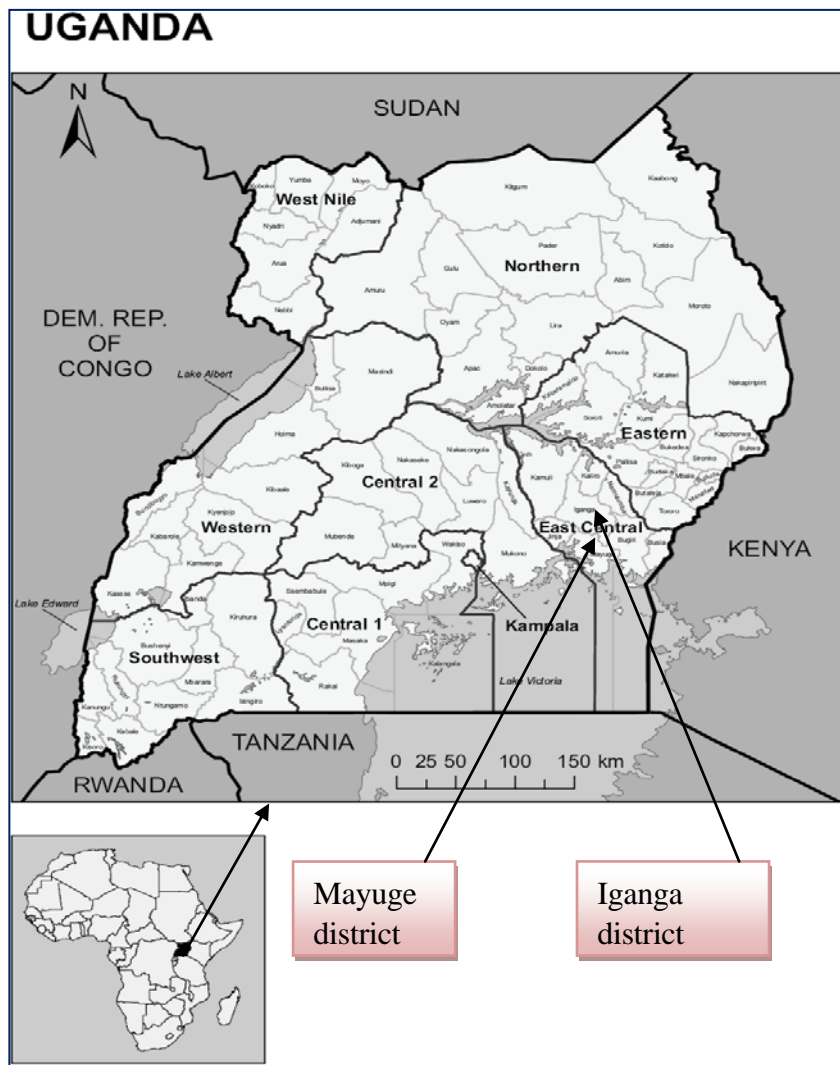

Figure 8: Showing study site districts

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 figure 9. 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)

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 6 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)

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, the 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 depict 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 12) 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 **<u>failed to suckle</u>** in the last 24 hours. When you check on the baby you find that the cord is still attached but with a **<u>smelly fluid oozing</u>** out and parts of the baby's body are covered with **<u>pustules.</u>**
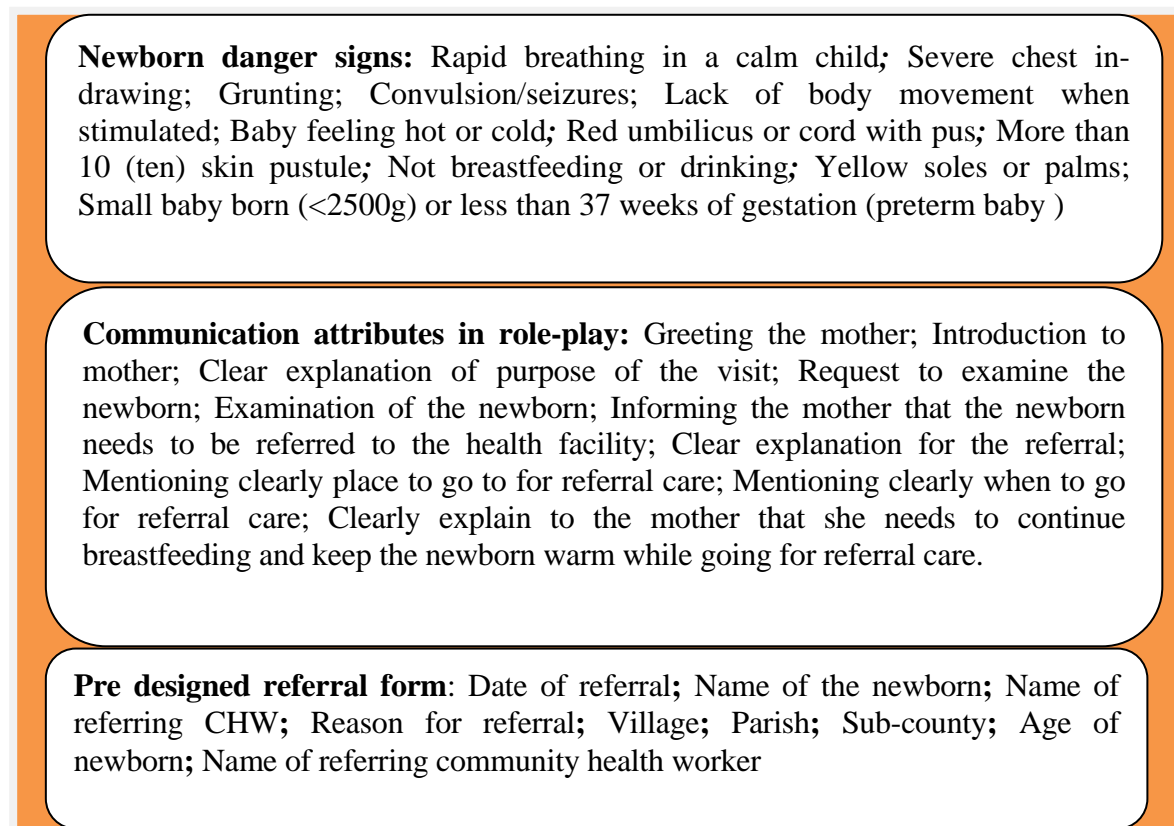
Case-vignette 2: A father of a newborn in your work area comes and reports to you that his 3 week old baby is not well. You quickly go to check on the baby and you are told that the baby cries a lot but keeps quiet after suckling. The mother complains that the baby wants to suckle all the time and feeds 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 **<u>feeling very hot</u>** and also pushing its head backwards. When you ask to be shown the baby you find that the **<u>baby's neck and limbs are difficult to move</u>** but keep jerking. The baby also looks **<u>very pale</u>** and is **<u>small, weighing about two kilograms.</u>**

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 **<u>no power in all the limbs,</u>** has **<u>difficulty in breathing</u>** and **<u>feels cold.</u>** 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 (<2500g) 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 (figure 9), were selected for assessment for readiness to care for sick newborns. They included one district hospital, one 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 the 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 personnel and the technology (e.g. blood transfusion capability) may facilitate compliance with referrals. Both mothers and fathers can make decisions to comply with referrals but the mothers are sometimes limited by finances.

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 REFERRAL OF SICK NEWBORNS AND THOSE FOR POSTNATAL CARE BY COMMUNITY HEALTH WORKERS (II)

Out of the 57 CHWs evaluated, the majority were females (40 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 identified 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

<div align="center">

Box 2: Summary of key findings

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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. Sixty three percent 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 six in ten of the CHWs 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.

4.3 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%). Sixty three percent (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. The biggest proportion, 108/292 (37%) of the sick newborns were taken to Health Centre IIs (Figure 13).

Most 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%).
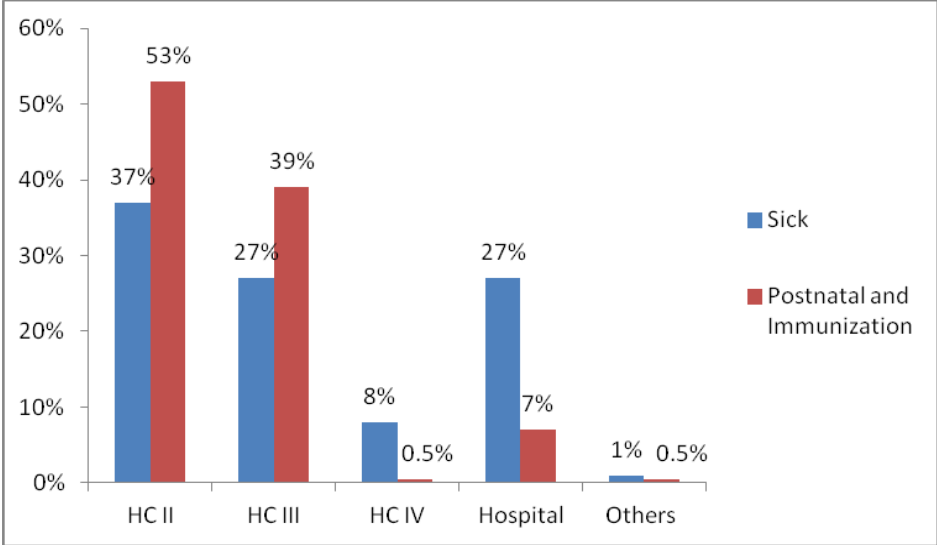
Figure 13: Type of health facility where caretakers of sick and healthy newborns sought care.

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]*

Of all the referrals, 53% were referred for immunization and postnatal care and 47% because they had at least one danger sign. Over 60% of the caretakers complied and sought referral care within 24 hours. However, caretakers of the sick newborns complied more than those referred for immunization and postnatal care (74% versus 53%, p<0.001).The sick newborns (37%) were mainly taken to HCIIs for referral care. The most common reasons mentioned for non-compliance included: "the mother was sick" (50, 19%) (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". Young mothers (less than 20years), caretakers of sick newborns, and caretakers who received a reminder visit from a CHW were more likely to comply with referral advice than their counterparts.

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.

4.4 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. There were no significant differences among the skilled health workers by cadre or health facility type.

Box 4. Summary of key findings

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. Sixty six percent 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.

V.   DISCUSSION

5.3 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.

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 identifying 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 through 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 provide 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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TITLE PAGE

Title: "As long as the umbilical cord gets off, the child ceases to be called a newborn:"

Sociocultural beliefs and newborn referral in rural Uganda

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CKN conceived and designed the study together with DG, JK, PW, and SP. CKN and JK collected data with supervisory guidance provided by JK and SP. CKN JK and SP conducted

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Key words: care-seeking; newborn; neonatal; qualitative; referral; socio-cultural influences; Uganda

Abstract

Background: The first week of life is the time of greatest risk of death and disability, and is also associated with many traditional beliefs and practices. Identifying sick newborns in the community and referring them to health facilities is a key strategy to reduce deaths. Although a growing area of interest, there remains a lack of data on the role of sociocultural norms and practices on newborn healthcare-seeking in sub-Saharan Africa and the extent to which these norms can be modified.

Objective: To understand the community's perspective of potential sociocultural barriers and facilitators to compliance with newborn referral.

Method: In this qualitative study focus group discussions (n=12) were conducted with mothers and fathers of babies aged less than 3 months. In addition, in-depth interviews (n=11) were also held with traditional birth attendants and mothers who had been referred by community health workers to seek health facility-based care. Participants were purposively selected from peri-urban and rural communities in two districts in eastern Uganda. Data were analysed using content analysis.

Results: The community definition of a newborn varied, but this was most commonly defined by the period between birth and the umbilical cord stump falling off. During this period newborns are perceived to be vulnerable to the environment and many mothers and their babies are kept in seclusion, although this practice may be changing. Sociocultural factors that influence compliance with newborn referrals to seek care emerged along three sub-themes: community understanding of the newborn period and cultural expectations; the role of community health actors; and caretaker knowledge, experience, and decision-making autonomy.

Conclusion: In this setting there is discrepancy between biomedical and community definitions of the newborn period. There were a number of sociocultural factors that could potentially affect compliance to newborn referral. The widely practised cultural seclusion period, knowledge about newborn sickness, individual experiences in households, perceived health system gaps and decision- making processes were facilitators of or barriers to compliance with newborn referral. Designers of newborn interventions need to address locally existing cultural beliefs at the same time as they strengthen facility care.

Background

The neonatal period is only 28 days and yet accounts for 44% of all deaths in children younger than the age of 5 years globally (1). In year 2012 approximately 35 000 newborns in Uganda died during their first month of life (1). Three-quarters of these deaths occur during the first 7 days of life (2), making the first week of life the most risky across the lifespan. The main causes of death during the newborn period are different from those of later childhood (3). More than any other age group, sick newborns can rapidly deteriorate and may die in a matter of hours. Yet newborn health issues have only recently begun to receive specific

attention in policy and programmes (4). Understanding local practices and beliefs during the first month and first week are critical to optimise delivery of care and promote healthy behaviours to ensure newborn survival.

A period of confinement or seclusion following delivery has been described in different settings including Tanzania, Senegal and Bangladesh, and is believed to protect the newborn from ancestral spirits and bad omens as well as infections and the cold (5-7). This seclusion period may pose a barrier to seeking care. Recognising illness and making a decision to seek care was identified as the main avoidable factor in 50% of newborn deaths in one study in eastern Uganda (8). The World Health Organization currently recommends home visits during the first week of life (9) to improve newborn survival (9). Depending on national policy, home visit activities range from preventive and promotive care to curative care. In addition, counselling, assessing for danger signs and referring sick newborns for health facility-based care are conducted.

The Uganda Newborn Study (UNEST) is a cluster randomised controlled trial designed to test a community-based care package for maternal and newborn health, including home visits by community health workers (CHWs) during pregnancy and the first week of life (10). While newborn care practices have been evaluated in UNEST (11-12), there is little data on the importance of local sociocultural norms and practices related to timely care-seeking. This qualitative research sought to understand the community's perspective of potential cultural barriers and facilitators to compliance with newborn referral. This paper is the eighth in a series on UNEST.

Methods

5

Study setting and design

The study was conducted in Iganga and Mayuge districts in eastern Uganda, within the Iganga-Mayuge Health Demographic Surveillance Site (HDSS) (13). The HDSS consists of 65 villages that are predominantly rural. Thirteen of these villages are peri-urban and form Iganga Town Council. The HDSS population is 80 000, with the main economic activity being subsistence farming. Other occupations include small-scale businesses such as grain milling, market vending, motorcycle transport, and civil service employment. The predominant ethnic group in the HDSS is the Basoga, whose indigenous language is Lusoga. The HDSS is served by one 100-bed hospital, six health facilities offering out- and in-patient services, and seven outpatient-only facilities. (14) In Uganda CHWs are integrated into national Village Health Teams which serve as volunteers at village level (15).

Within UNEST locally recruited CHWs worked in their respective villages and visited households twice during pregnancy and three times during first week after birth, on days 1, 3 and 7, for counselling on health behaviours and danger signs, and newborn assessments (12).The CHWs were trained and expected to identify the following signs of severe illness: convulsion, hotness or coldness, failure to breastfeed, rapid breathing in a calm baby, grunting, lack of movement on stimulation, yellowing, in-drawing of chest, umbilical cord with pus, and skin papules with pus, with special attention to babies who were born preterm and/or of low birthweight.   During the home visit the CHWs advised the mothers to seek care from a health facility immediately if a danger sign was noticed. In addition, CHWs also referred babies born outside health facilities for immunisation and postnatal care. In all the referral cases a CHW wrote a referral note and gave it to the mother to present at the health facility for faster assistance than if they were to seek care without a referral.

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This qualitative study was conducted between January and September 2012. Homogeneous focus group discussions (FGDs) and in-depth interviews (IDIs) with mothers, fathers and traditional birth attendants (TBAs) were used to explore the community's perspectives in terms of knowledge of norms, perceptions and practices during the newborn period which might impact on danger sign recognition, care-seeking practices and decision-making processes, as well as referral compliance. The TBAs were considered important informants with unique perspectives on newborns and healthcare-seeking, since many women in the study area seek care from traditional healthcare providers, even if they do end up delivering at the health facility.

The field research team comprised a public health specialist and a medical anthropologist with social scientists as research assistants.

Sampling frame and sampling procedures

The selection of study participants was purposive, targeting community members believed to have rich information about sociocultural factors that could influence compliance with newborn referral advice. Eight rural and 4 peri-urban villages were randomly selected from the 65 villages in the study area to host the FGDs and IDIs. FGDs were categorised by geographical location, sex (male/female); age (18-25-year-old and 26-49-year-old females were split), and place of residence (rural/peri-urban). The mothers who participated in IDIs were further categorised according to compliance with referral (complied/did not comply). The rationale behind categorisation was to obtain maximum variation in the views of the study participants (16). Attributes like geographical location and mother's characteristics have been documented as influencing utilisation of healthcare services (17).

Recruitment of study participants

Male and female participants for both the FGDs and IDIs were purposively selected from the villages with the assistance of the local village head. Participants were required to have children aged less than 3 months in order to identify individuals with knowledge and experience of the current norms and practices surrounding newborn care in this setting. UNEST staff and local CHWs provided information used to identify the homes of mothers who participated in the IDIs. None of the persons invited for interviews or discussions declined to participate.

Data collection and processing

Research assistants whose mother tongue is Lusoga and who were experienced in qualitative data collection methods participated in data collection either through note-taking or moderating the discussions. They were trained on the study objectives and familiarised with the discussion and interview guides. Two pilot FGDs and one IDI were conducted in a village neighbouring the study area to test the flow of the discussions and interviews and how long each would last. Thereafter some questions were rephrased for clarity and others rearranged to facilitate logical flow of the discussion.

A total of 12 FGDs were conducted. Each FGD comprised 5-10 participants and lasted no longer than 2 hours (18). In addition, in-depth interviews were conducted with TBAs (n=3) and women who had a sick newborn and subsequently received a referral by a CHW to seek further care (n=8). This was done to triangulate the issues expressed during the FGDs and deepen understanding of the social and cultural factors influencing care-seeking.

The FGD guide was based on questions formulated according to themes from previous research findings, but remained flexible to address emerging issues during the discussions. IDI participants were asked similar introductory questions as in the FGDs, but were also asked and probed for information such as why they complied with referral or why they did

not comply, and who was responsible for this decision making. In the case of TBAs, their role in caretakers' compliance and decision making was also ascertained. The FGDs and IDIs were held at venues agreed upon by the participants and free from interruption such as from onlookers and traffic.

All interviews and discussions were conducted in Lusoga, the main local language in the study area. They were all tape-recorded and notes were taken. The note-takers immediately expanded the notes after the interviews and discussions, in preparation to supplementing the recordings at a later date during the verbatim transcription in cases where recordings were not audible enough. Emerging issues were identified and explored further in subsequent interviews and discussions.

The research assistants provided verbatim transcriptions of the recordings with direct translation into English. Local terms that could not easily be translated into English were kept in Lusoga. The data were analysed using content analysis. (19) The conventional content analysis approach was used, where codes are directly derived from the data text. (20) The FGD and IDI scripts were independently read by three people: the principal investigator, a medical anthropologist and a social scientist. These readings were used to generate codes that were discussed and agreed upon during a review meeting and used for data analysis. The principal investigator developed the final code book, closely guided by the medical anthropologist. The code book was accessible to all research team members.

The text data were systematically synthesised. First they were coded into meaning units, which were reduced into condensed units, followed by grouping them into sub-themes, and then the final themes as agreed upon by the study team (table 1). This analysis was led by the medical anthropologist. The ATLAS.ti version 7.0 software program was used for qualitative

data management and analysis. Further development of meaningful units and interpretation was done by all of the authors. Disagreements were resolved through consensus discussions.

Ethical considerations

The protocol for this study was reviewed and approved by Makerere University College of Health Sciences, School of Public Health Higher Degree Research Committee and the Uganda National Council of Science and Technology. The research team members explained the purpose of the study to the participants and emphasised that enrolment into the study was voluntary. Individual written consent was sought from both FGD and IDI participants. Illiterate participants were verbally informed of the terms of the study and provided consent through thumbprints. Only participants aged 18 years and above were recruited for interviews and discussions. No money or incentives were offered to the study participants, although a soft drink was given to each participant during the discussions. Interviews and discussions took place in privacy, and to ensure confidentiality FGD participants were assigned identification numbers during discussions and transcription. In addition, all files were password protected.

Results

The sociodemographic profile of the participants is presented in Table 2. A total of 48 women participated in the 8 FGDs and 8 IDIs, with a mean age of 28.9 years and range of 18-44 years. The majority of participants were married (n=44), had attained primary education (n=34) and were engaged in subsistence farming (n=42). Three TBAs were interviewed, aged 60, 50 and 48 years. A total of 23 men participated in four men's FGDs, with a mean age of 39.7 years and range of 22-57 years. The mean number of children fathered by these participants was 5 with a range of 1-14. The men were mainly subsistence farmers (n=9); an

equal number (n=9) had attained ordinary-level secondary education. Amongst the 8 women interviewed for IDIs, 4 mothers had sought referral care for their newborns (complied) and four women had not.

The results of the FGDs and IDIs revealed three broad themes that may influence care-seeking and compliance with referral: community understanding of the newborn period and cultural expectations; the complexity of community health actors; and caregiver knowledge, experience and decision-making autonomy (Table 1).

Community understanding of the newborn period and cultural expectations
All the FGD and IDI participants mentioned and agreed that the local term for a newborn in this setting is *nakaghele* while the mother is known as *omwibo,* meaning "one who has just delivered". There was no single common definition of the newborn period. Few respondents conveyed the epidemiological definition, that is, from birth through 28 days of life. Rather, often participants described different time-points as marking the end of the newborn period. These included commencement of supplementary feeding, attainment of specific growth milestones like walking, and ability to care for self. For example, one woman in the FGD said "A newborn can go up to 6 months because that is when the child starts eating and drinking", while a man in another FGD said: "a newborn stops at 8 months because when my child starts walking it has come out of newborn size".

The trained CHWs reportedly provided a consistent definition of the newborn period as that from birth to 1 month of age, as narrated by an informant during an interview: "The village health worker [*mentions the name of the CHW*] said a newborn is a 1–month-old baby". However, the community's most common indicator of the end of the newborn period was umbilical cord detachment. The participants frequently reported that the umbilical cord

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detachment took place within a week after delivery, and this marked the end of the newborn period, as explained by one male FGD participant:

"A child '*nakaghwere*' [*the young one*] is the one who is kept in the house and the cord has not yet got off ..., when it gets out of the house it stops being a newborn after 7 days, then it ceases to be a newborn. It is our cultural practice, as long as the cord gets off it ceases to be called a newborn."

In many discussions and interviews a newborn was consistently described as "a child who is delicate" and needed extra care and protection, including shielding from sunshine, coldness and disease vectors such as mosquitoes and rats. One man in the FGD explained that "you cannot just hold the newborn anyhow, you must be very careful with extra care ..., not putting the baby in the sun and cold ..., keep baby away from insects, even rats, ... laughter...". In another FGD a woman explained that "A newborn is defined from day 1 of birth up to 1 year because you have to breastfeed, care about him all the time … and if left to the cold, it might get this fever pneumonia that comes with the cold."

One of the distinctive norms is the postnatal seclusion or confinement period known as *ekisanda* [dry banana leaves]. The practice does not have a specific number of days but it begins immediately after birth and continues until the newborn's umbilical cord falls off. This was explained by one male FGD participant: "The mother and *nakaghwele* [*newborn*] when still in *ekisanda* [*seclusion*] cannot move out until after the umbilical cord drops off … and at that moment it will be called *omwana wawa* [*a grown-up child*]".

Culturally mothers are expected to strictly observe this seclusion period and stay indoors, irrespective of their place of delivery. However, this was reported to be changing, especially in the peri-urban areas, as explained by one informant: "For us here in town we can't stay in

house without moving out, you have to go to the market and buy food every day, even take the baby if sick..." (IDI mother who complied with referral advice).

A woman in one peri-urban FGD said that it was possible to violate the seclusion period: "But nowadays for me … I have to take my baby to the hospital when sick, whether the umbilical cord still on or not" (mother, FGD). Similarly, a man in the FGD held in the peri-urban area also reported that health workers instruct them to take babies for immunisation within the first week after delivery: "The health workers teach us to take the child to the health centre for polio prevention, even though it has not yet made 7 days" (father, FGD).

Traditionally during this period a woman who has just delivered is supposed to sleep on the floor on dry banana leaves or on a mattress with a few dry bananas leaves underneath. During this period the baby is not supposed to be touched by outsiders, not even siblings. This seclusion period is intended to protect the baby against evil spirits and infections, and the coldness that may lead to sicknesses such as pneumonia. There does not appear to be a difference in gender regarding the period of seclusion, as mentioned by one informant: "Whether a boy or a girl, they are not taken out so long as the umbilical cord is not yet off" (IDI mother who did not comply with referral advice).

However, several participants indicated that in the case of a critical situation (e.g. a funeral of a close family member), a woman could be allowed to attend the funeral and burial. Often participants made provisions to violate the confinement and seek health care for sick babies and those who needed routine immunisation. This was one practice reported that was in conflict with seclusion practices. However, a few participants reported the desire to strictly observe the seclusion period unless a misfortune happened, as one woman said: "I cannot go out before the umbilical cord drops off -- maybe if my mother or father died" (mother, FGD).

After the umbilical cord falls off a number of rituals, *okukuza omwana* (recognising that the baby is a grown-up) are performed, such as the naming ceremony. Other practices include ritual bathing, throwing away the dry banana leaves from the seclusion room, parents of the newborn engaging in sexual intercourse for the first time since delivery (or a ritual to symbolise the same), and feasting, as participants described:

> "Ceremonies are performed after the baby's cord has dropped off. We call it *okukuza omwana*. The mother throws away the dry banana leaves, the father and mother of the baby sleep together for the first time after delivery, and depending on the clan of the family, different foodstuffs like sim-sim sauce and goat's meat are prepared for the family members to eat." (IDI, TBA)

> "When the baby's umbilical cord is off, [the mother and baby] move outside, pour water on the roof and it comes and falls on the child" (father, FGD).

The umbilical cord is kept secure by the mother or given to the father of the newborn. The umbilical cord is kept to be used in another ceremony of confirming paternity at a later date.

The role of community health actors

Community care providers such as CHWs, private drug sellers and TBAs play various roles with regard to maternal and newborn care. Two TBAs reported that they refer sick newborns and pregnant mothers who are first-time mothers and those who have had five or more deliveries, as one explained: "I once sent a mother to take the baby who had a cord with pus to Iganga Hospital; the mother had put powder on it".

 Many of the FGD participants reported that CHWs encourage community members to seek care from health facilities, and also agreed that families comply with referral advice given by

the CHWs, as mentioned by one of the women in the FGD: "Our village health worker told us that before we buy drugs for the baby from shops, we should first take them to Government health centres. So we also follow her advice."

The participants continued to mention that CHWs offered them health education about newborn care and motivated them to seek referral care by giving them referral notes, as one woman in the FGD stated: "When the CHWs are teaching us, they tell us about the bad signs, when you realise that the baby has some of those bad signs, you go to the CHW…, the CHW gives you a note [*referral slip*] and you go to the health facility".

However, for some community members the first point of care-seeking following referral may not be the health facility, even when they have been counselled. One informant reported that some caretakers first seek care from [1]drug shops and traditional providers, given their proximity, especially during the seclusion period. Depending on the baby's outcome after receiving initial care, they may decide to proceed to a health facility, as stated by a mother during an interview: "Some people first go to drug shops and traditional healers and then to the Government health facilities if the baby does not get well."

Another reason given for not immediately seeking formal care following the CHWs' referral advice was the belief that some conditions are best managed by traditional healers or community specialists. Compliance with referral can be based on whether the cause of the sickness is believed to have a traditional or biomedical solution. One mother stated during the interview: "... when the baby has a strange disease like the yellow body, you go to a traditional healer" (IDI mother who did not comply with referral).

Caretaker knowledge, experience, and decision-making autonomy

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Caretaker knowledge of newborn danger signs

FGD and IDI participants often mentioned symptoms that indicate severe illness, such as failure to breastfeed, convulsions and umbilical cord with pus. These symptoms are in agreement with those classified as newborn danger signs by biomedical health workers. However, signs which do not qualify as danger signs were occasionally mentioned by participants, and these included 'false teeth', 'extra digits' and 'tongue tie'. The participants agreed among themselves that newborns with danger signs should be taken for facility-based care. The community's knowledge of danger signs seemed to influence compliance with referral. Caregivers who could describe the danger signs promoted by CHWs were positively inclined towards complying and seeking referral care, as stated by one woman in the FGD: "A baby may have a problem with the umbilical cord, like you see blood or pus coming out of the cord. You go to the CHW if the CHW is able to help; she can help and thereafter can send you to a health facility."

Caretaker experiences

During the FGDs and IDIs, participants mentioned and narrated negative experiences from previous interactions with the health system. These reflected poor quality of care at the health facilities, such as rude health workers, stock-outs of medicines and absenteeism from work, especially on weekend days. These were highlighted as possible barriers to newborn referral compliance. Participants expressed the view that some health workers were rude, and thus discouraged caretakers from seeking referral care. It was also reported that health workers at lower-level facilities did not work during evening hours or weekends, so that if a newborn is referred during a weekend, the caretaker has few options. Similarly, perceived poor quality of care, including lack of drugs and supplies, deters caretakers from seeking a higher level of care, especially if the distance to the facility is far.

1Retail shops selling medicines on a small scale in villages

Some participants reported that there were drug stock-outs at health facilities and that they were told to buy medicine for their newborns. With such experiences some caretakers may opt for other alternatives to treat the sick newborns. Acknowledging these constraints and perhaps reflecting pervasive beliefs in traditional remedies, health workers were also reported to have advised parents to seek care in the informal health sector, as one mother reported: "Sometimes health workers when they don't have that medicine they tell you to go back and [get] local medicine" (mother, FGD).

Experiences with stock-outs in particular were raised as potential barriers to future compliance with referral. At the same time, positive experiences such as the presence of qualified personnel and high technology like blood transfusion services were possible motivators to seeking care from health facilities, as expressed by one informant mother who complied with referral: "I took the baby to Nakauvle [district hospital] because there are doctors who can put in blood."

Informants who did not comply with referral reported experiences related to the health status of the mother and family members, poverty, and weather conditions as factors that prevented them from complying with referral. One of the informants explained: "I was unwell, still bleeding and could not walk to take the baby". Another mother said "I did not go because it had rained the whole day and I had no money for transport," and another that "I was caring for another sick child. I decided to wait and go another day".

Decision making

According to most FGD participants the decision to seek referral care when recommended rested primarily with the father or mother rather than other family or community members. They were in agreement with a TBA who reported that as an outsider to the family, she was not responsible for making any decisions when the baby was referred by the CHWs; her role

ends at delivering the babies. She explained: "When the CHW [*mentions CHW's name*] tells the mother to take the baby to Nakavule [Hospital], it is for the family to decide if they take the baby, not me -- my job is to help the mother deliver the baby."

Occasionally some women expressed that while the mother can take a decision to seek care, she often does not have the finances to be able to do so. Other participants were of the view that since the father provides money, he ultimately makes the decision, as narrated by one woman in the FGD: "You a woman may decide to take the baby after being referred, but if you don't have the money you find yourself unable to go." Another woman in the FGD added: "Now if the baby refuses to breastfeed or has a high temperature, I told you, our village health workers write letters for us and tell us to take the babies to the health facility, but it's for the husband to decide." During the interview another mother emphasised that: "He has to decide because he is the one to pay the hospital bills, so you cannot force him" (IDI mother who did not comply with referral).

Discussion

Sociocultural factors influencing community newborn referral compliance in eastern Uganda were broadly categorised into those related to the community understanding of the newborn period and expected practices around this time, the varying and overlapping roles of community health actors, and caretaker knowledge, experience and decision making. These were the main themes that emerged linked to whether or not families comply with community referrals. In general, caretakers portrayed willingness to comply with newborn referrals, for example from CHWs, but there were also barriers to their ability to seek care.

We found a discrepancy between the biomedical and community definitions of a newborn. While some of the study participants described the newborn period as lasting through the first year, the predominant definition limited the newborn period until the baby's umbilical cord stump fell off. The newborn period was linked to a number of strongly held traditional practices, including seclusion for mother and baby in some families, which may affect care and care-seeking. A seclusion period is well described in the literature from other settings (7, 21-23), although in this setting the time was shorter than the commonly held 40 days of life (24-25). While this practice provides an opportunity for the mother to rest and regain strength, establish breastfeeding, and bond with her baby, it might also limit the ability to seek care outside of the home during the time of greatest risk (24-26). However, participants in this setting reported a possibility of breaking the seclusion and seeking referral care if the illness is severe enough. Participants expressed that the seclusion period is a traditional practice, but that if necessary the baby can be taken for facility-based care.

Recognition of danger signs and perceiving certain symptoms as important, eliciting seeking of care, may have been due to counselling by the CHWs. For example, a bleeding cord or one with pus was associated with the baby having severe illness, and prompted caretakers to comply with referrals. CHWs are recognised in their capacity as health promoters for women and newborns in this setting, a finding that has been also been echoed in western Uganda, where the integrated community case management programme for children under 5 years of age has been rolled out (27).

 Both mothers and health workers noted that the referral slips given to women by CHWs to present at health facilities increase legitimacy and facilitate prompt treatment by the health workers (27). However, families do not always go directly to formal health services after referral. Traditional providers and local private clinics and drug sellers were more likely to be

the first point of care, especially in rural areas and if the baby is referred in the evening or on weekends. This has implications for newborn survival, despite the increased care-seeking, since such places have limited capacity for and quality of sick newborn management, and may lead to delays in receiving appropriate care. Referrals from community level were not just given by CHWs, and the reported referral by TBAs is important emerging information that needs more study.

In one review of home-based newborn care in Bangladesh, the use of traditional care and home remedies was preferred to formal health services (28). Only when the baby did not improve at home did the caretaker consider seeking care from the health facilities. In Ghana only 61% of newborns with a serious illness were taken outside the home to seek care (29). This phenomenon of seeking facility-based care after failure to improve has also been reported amongst older children in Tanzania (30). Informal healthcare providers play an important role in offering health care because of their proximity and availability in the communities. Involving them early on in community-based interventions should be explored, and it should also be examined how they can support care-seeking from the formal health sector for newborn illness and reduce delays in receiving newborn care.

Decisions to seek referral care ultimately depend on the availability of finances, which are usually controlled by the husband, who is most often the head of the household. In general we found that the source of the decision to seek care was mixed. In other families the father was viewed both as an overall decision-maker in the home in addition to providing the money. This is similar to a finding reported in a study that explored how decisions are made in seeking maternal care in Burkina Faso (31). The same opinion that men dominate in decision making at household level was reported by Mbizvo et al. in Zimbabwe (32). However, we also found that mothers often believed that they had a right and that it was their role to make

a decision in relation to the baby's health, although sometimes they may not have had the money to go for referral care.

Past experiences with seeking care from the formal sector and perceived quality of care seemed to have a role to play in compliance with the CHWs' newborn referral advice. Past experience with drug stock-outs, health work absenteeism and rudeness could lead to non-compliance in this setting, as reported by Waiswa et al. (33). This experience is not unfounded; previous studies show that families in Uganda may not receive high-quality care for their sick children once they do seek care (27, 34-35). The health system quality gaps thus need to be overcome to further motivate caregivers to comply with referral advice.

This study has some limitations. Transferability of some of the findings may only apply to the study setting and areas with similar cultural norms. However, findings regarding decision making and health system gaps as barriers to compliance with newborn referral may be more widely applicable. The use of FGDs first followed by IDIs may not be considered the normal approach, but in this study we needed to understand the broader picture before narrowing down to the participants who experienced the newborn referrals.

We aimed at achieving trustworthiness in this study by triangulation of the data collection methods, providing a description of quotes from the participants for accuracy of representation, describing the data analysis process to show that the findings emerged from the data, with the team comprising experienced researchers in the method and topic of study.

Conclusion

In this setting a discrepancy exists between the biomedical and community definition of the newborn period. There were a number of sociocultural factors that could potentially affect compliance to newborn referral. Despite the widely practised norm of a seclusion period, acceptance to seek referral care during this period seems feasible, particularly if the illness in the newborn is perceived as severe. Social factors, including knowledge about newborn sickness, individual experiences at households, perceived health system gaps and decision-making processes, were facilitators of or barriers to compliance with newborn referral.

Designers of interventions for newborns need to address locally existing cultural beliefs at the same time as they strengthen facility care. Additional emphasis on all danger signs should be made during CHW counselling sessions in pregnancy and the early postnatal period. The differences between illnesses with a perceived biomedical solution compared to those considered suitable for treatment by traditional remedies and the subsequent impact on care-seeking patterns requires more investigation. Similarly, more research is needed to identify factors that can reduce delays in care-seeking, including how to involve trusted community health actors such as the TBAs.

Table 1. 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 1 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 recognised by health workers	CHWs 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 immunised from because they send vaccines from Magada every end of the month	Mothers are aware and immunise children at outreaches	Private clinics used for immunisation 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 signs	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

Table 2. Sociodemographic characteristics of men and women who participated in FGDs and IDIs

	Men	Women
Variables	**N=23**	**N=48**
	n (%)	**n (%)**
District		
Iganga	12 (52)	16 (33)
Mayuge	11 (48)	32 (67)
Residence		
Peri-urban	10 (43)	14 (29)
Rural	13 (57)	34 (71)
Marital status		
Single / never married	5 (22)	4 (8)
Married	18 (78)	44 (92)
Education status*		
Primary	9 (39)	34 (71)
Secondary ordinary	6 (26)	8 (17)
Secondary advanced	2 (9)	1 (2)
Tertiary	3 (13)	0 (0)
No education	3 (13)	5 (10)
Occupation§		
Peasant	14 (61)	40 (83)
Businessman	6 (26)	4 (8)
Catering	0 (0)	1 (2)
Housewife	0 (0)	2 (4)
Tailor	0 (0)	1 (2)
Head teacher	1 (4)	0 (0)
Primary teacher college tutor	1 (4)	0 (0)
Student	1 (4)	0 (0)

* Years of formal education: Primary (1-7 years), Ordinary level secondary (8-11 years), Advanced level secondary (12-13 years), and Tertiary (14+ years).

§Categories for men and women do not add up to 100% due to rounding off of the values.

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Community health workers – a resource for identification and referral of sick newborns in rural Uganda

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Abstract

OBJECTIVE   To determine community health workers' (CHWs) competence in identifying and referring sick newborns in Uganda.

METHODS   Case-vignettes, observations of role-plays and interviews were employed to collect data using checklists and semistructured questionnaires, from 57 trained CHWs participating in a community health facility–linked cluster randomised trial. Competence to identify and refer sick newborns was measured by knowledge of newborn danger signs, skills to identify sick newborns and effective communication to mothers. Proportions and median scores were computed for each attribute with a pre-defined pass mark of 100% for knowledge and 90% for skill and communication.

RESULTS   For knowledge, 68% of the CHWs attained the pass mark. The median percentage score was 100 (IQR 94 100). 74% mentioned the required five newborn danger signs unprompted. 'Red umbilicus/cord with pus' was mentioned by all CHWs (100%), but none mentioned chest in-drawing and grunting as newborn danger signs. 63% attained the pass mark for both skill and communication. The median percentage scores were 91 (IQR 82 100) for skills and 94 (IQR 89, 94) for effective communication. 98% correctly identified the four case-vignettes as sick or not sick newborn. 'Preterm birth' was the least identified danger sign from the case-vignettes, by 51% of the CHWs.

CONCLUSION   CHWs trained for a short period but effectively supervised are competent in identifying and referring sick newborns in a poor resource setting.

keywords community health workers, knowledge, communication, skill, newborn, danger signs, referral, Uganda

Introduction

Four in ten of child deaths worldwide are newborns, and in Africa, the newborn mortality rate (NMR) is 35.9 deaths per 1000 live births (Oestergaard et al. 2011). In Uganda, 38 000 newborn deaths occur each year (Mbonye et al. 2012) and the NMR is 27 per 1000 live births (UBOS 2011). Globally, complications from preterm births are the leading cause of newborn deaths (29%), followed by asphyxia (23%) and infections due to sepsis and pneumonia (25%) (Black et al. 2010).

Evidence-based newborn care interventions at home can prevent 30–60% of newborn deaths in high mortality settings under controlled conditions (WHO 2009). Among the interventions is home visit by community health workers (CHWs) to pregnant mothers, and immediately after birth to assess newborns' health and treat,

or refer sick ones. This intervention reduced neonatal mortality by 34–62% in Bangladesh and India (Bang et al. 1999; Baqui et al. 2008). However, experts are uncertain whether the success demonstrated in improvement of newborn outcomes in Asia can be replicated elsewhere due to social–cultural and contextual variations (Lawn et al. 2009).

A previous study in rural eastern Uganda showed that half of newborn deaths were due to delays in recognising problems or making the decision to seek care, and about 30% were due to delays in receiving quality care at healthcare facilities (Waiswa et al. 2010a). After these findings, a community health facility–linked intervention in the Uganda Newborn Survival Study (UNEST) (Waiswa et al. 2012) was implemented with the aim to improve newborn outcomes. The current study was conducted to evaluate whether the trained CHWs have

adequate knowledge and skills to identify newborns with possible danger signs, and whether they can effectively communicate to mothers to immediately seek care for their sick newborns from health facilities.

Materials and methods

Study setting

This study was conducted in November 2011, in the Iganga–Mayuge Health Demographic Surveillance Site (HDSS), located in two eastern Uganda districts of Iganga and Mayuge, approximately 120 kilometres east of Kampala, the capital city of Uganda. The HDSS covers a population of 74 894 people and is mainly rural. 10 863 are children under 5 years and 17 782 are women of reproductive age. The people predominantly practise subsistence farming among other occupations like business, market vendor and professional jobs (HDSS 2011). There are five health facilities that provide maternity services, and 68% of deliveries occur at health facilities, of which 71% are attended by skilled health workers (UBOS 2011). The NMR is estimated at 30 deaths per 1000 live births (HDSS 2011).

Background on UNEST study

Sixty-one literate CHWs were selected and trained for 5 days between June and July 2009 (Waiswa *et al.* 2012). The CHWs were trained in groups of 20 together with their supervisors (health workers), to enable them understand the CHWs' training scope and also get acquainted with CHWs. The methods of training included: role-plays using job aids, questions and answers, group discussions followed by plenary presentations, demonstrations and feedback sessions by facilitators. The CHWs' roles during pregnancy and after delivery were emphasised, including health education, screening for danger signs (Table 1) and counselling for referral. Other topics covered are shown in Panel 1. At the commissioning ceremony, CHWs were presented with a certificate of attendance, job aids, a bag and a T-shirt-labelled UNEST for identification in their respective villages.

The CHWs were supervised during monthly meetings with their supervisors, by directly observed supervision (DOS) and quarterly meetings, all characterised by reinforcing knowledge and skills (Panel 1).

Study population

All 61 CHWs under the UNEST study were eligible for this study. Four were excluded after they were randomly

Table 1 List of newborn danger signs, communication and referral form attributes

New born danger signs*	Rapid breathing in a calm child
	Severe chest in-drawing
	Grunting
	Convulsion/seizures
	Lack of body movement when stimulated
	Baby feels hot or cold
	Red umbilicus or cord with pus
	More than 10 skin pustule
	Not breast feeding or drinking
	Yellow soles or palms
	†Small baby born < 37 weeks of gestation (preterm baby)
Required communication attributes	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 they need to keep the newborn warm and continue breastfeeding while being taken for referral care.
Pre-designed referral attributes on referral form that were completed	Date of referral
	Name of the newborn
	Name of referring CHW
	Reason for referral
	Village
	Parish
	Subcounty
	Age of newborn
	Name of referring community health worker

*Adapted from continuum of care (WHO 2006).
†Community health workers did not weigh the newborns during home visits but checked on the immunisation cards or discharge forms for those who were delivered in health facilities.

selected and used in pre-testing the study tools. Hence, 57 CHWs participated in the evaluation, which was conducted 25 months after the initial training.

Measurements

CHWs' competence to identify and refer sick newborns was determined using tools adapted from training

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Panel I: Uganda Newborn Survival Study (UNEST) and CHW training package

Description of Uganda Newborn Survival Study IS-RCTN50321130

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 2010).

Study design

A cluster randomised trial in 32 control and 31 intervention villages, located in a demographic surveillance site with about 74 894 people in eastern Uganda.
   Intervention package:
- Trained health workers and provided supplies and equipment to strengthen maternal and newborn care services in health facilities
- Trained 61 CHWs to link communities and health facilities by:

  1) CHWs making two home 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 immunisation and post-natal care.

CHW supervision

The CHWs were supervised in three ways: i) monthly meetings with their supervisors at the health facility, ii) directly observed supervision (DOS) for the first 6 months of the intervention, where the supervisor used a standard checklist to observe how a CHW conducted antenatal and postnatal home visits uninterrupted. Thereafter, the supervisor corrected mistakes and reinforced the knowledge and skills of the CHW, and iii) quarterly meetings comprising of health workers, CHWs, DHT and UNEST members, and integrated with refresher trainings.
   Content of the training provided to CHWs regarding newborn care included
- Birth preparedness
- Cord care
- Thermal care
- Breastfeeding and initiation
- Kangaroo mother care
- Newborn danger signs
- Newborn referral
- Community mobilisation skills

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materials used in UNEST study. Competence was defined as having sufficient knowledge and ability to recognise sick newborns at a pre-defined pass mark, similar to a study that evaluated health workers' competence in maternal and newborn care in Pakistan (Ariff *et al.* 2010). We evaluated 3 attributes of the CHWs' competence: (a) knowledge about newborn danger signs, (b) ability to recognise newborn danger signs and (c) ability to effectively talk to mothers about newborn danger signs and counsel them to seek care from health facilities.

A structured questionnaire was used to evaluate CHWs' level of knowledge about newborn danger signs by asking CHWs to name 5 newborn danger signs they knew (unprompted), and to indicate whether a named sign was a newborn danger sign or not by answering true

or false (prompted). There were a total of 11 danger signs for the prompted questions (Table 1), as outlined in Uganda's National Newborn Standards (MOH 2010) and the newborn continuum of care (WHO 2006; Kerber *et al.* 2007). One score was awarded for each correct danger sign mentioned. CHWs' knowledge was adequate if they mentioned five newborn danger signs (unprompted), and if they correctly recognised all the 11 danger signs read to them (prompted). Thus, the knowledge component was allocated a minimum score of zero and a maximum of 16 points.

The structured questionnaire was also used to collect the CHWs' background characteristics including age, sex, marital status, education status, ethnicity, occupation, number of newborns referred in the last 25 months prior

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Panel 2: Case-vignettes used in the assessment of skills of CHWs to identify newborn danger signs

Case-vignette 1: During your work as 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 <u>failed to suckle</u> in the last 24 h. When you check on the baby you find that the cord is still attached but with a <u>smelly fluid oozing</u> out and parts of the baby's body are covered with <u>pustules.</u>

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 <u>feeling very hot</u> and also pushing its head backwards. When you ask to be shown the baby you find that the <u>baby's neck and limbs are difficult to move</u> but keeps jerking. The baby also looks <u>very pale</u> and is <u>small, weighing about two kilograms.</u>

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

*Note: only the underlined symptoms and signs were considered as danger signs in this study

to the study, period of working as CHW for UNEST study and past experience of working as CHWs prior to participating in UNEST.

To assess CHWs' ability to identify newborn danger signs, four case-vignettes were used. Case-vignettes have been used to evaluate skills of primary health workers in case management of serious illness among young infants (Gouws *et al.* 2005). Our case-vignettes were developed using sick newborn clinical notes from Iganga district hospital by the study investigators together with a consultant paediatrician who is a team member of UNEST. They were reviewed by another paediatrician independently of this study. Consensus was reached that three case-vignettes depicted sick newborns and one depicted a healthy newborn. The four case-vignettes used in this study are described in Panel 2. A total of 11 newborn danger signs were embedded in the four case-vignettes.

The case-vignettes were translated into Lusoga, the local language most commonly used in the study area, by a language specialist based at the HDSS. Trained interviewers (a public health specialist and three nursing officers) read out each case-vignette to a CHW at least three times and complemented it with pictures showing newborn-specific danger signs to ensure that the CHW understood the newborn in description.

For evaluation, a CHW was asked to point out whether the newborn in the given case-vignette had any danger sign or not, specify the danger sign(s), if any, in each of the 4 case-vignettes and actions they would take in each scenario. Each correct answer was awarded one

point and none for an incorrect one. The minimum score for the four case-vignettes was zero, and the maximum was 11 points.

The CHWs' effectiveness in communicating to mothers to seek health care for their sick newborns was evaluated using role-plays. Role-plays have been used in assessing communication skills among nurses working in an intensive care unit in New York (Krimshtein *et al.* 2011). Two aspects of effective communication by CHWs were assessed using tools adapted from UNEST supervision checklists: observing the CHW's communication skills to the mother in the role-play, and the quality of the completed pre-designed referral form. A consenting mother with a healthy newborn was identified from the study community and coached to participate in the role-play as if the newborn had fever and the baby's cord was smelly with pus. Each CHW was instructed to assume that the description of the condition of the newborn by the mother was correct. Using a pre-designed checklist, the interviewers critically observed and took note of every CHW's action as he or she communicated with the mother. Ten communication aspects (Table 1) were assessed. Each of these aspects was scored one point if done and none if not done. Every CHW was expected to perform all the 10 communication attributes. Regarding referral, the CHW was expected to request for a referral form, and complete it with all the eight necessary details as listed in Table 1. The pre-designed referral form was provided by the observer on request by the CHW in case (s) he found it necessary to use it after interacting with

mother. Each item filled correctly was scored one point and none if left blank. Thus, the communication component was allocated a minimum score of zero and a maximum score of 18 points.

Statistical analysis

Data were entered in Epi-Data software and exported to STATA version 10 for analysis. Regarding knowledge and ability to identify newborn danger signs from the case-vignettes, proportions were calculated and reported for the attributes scored as outlined above. The range and median scores attained by the CHWs were also computed.

For effective communication of CHWs, we calculated the proportion of CHWs who were able to display the required communication attributes as listed in Table 1, during the role-plays, and the proportion of CHWs who correctly completed the referral form with all the eight attributes listed in Table 1.

For each component, we computed a total score for every participant and the proportion of CHWs who attained the pass mark. Because there are no national references, for each component an arbitrary pre-defined pass mark was set. For knowledge, it was 100%, because this was considered to be a relatively easy task of mentioning only five newborn danger signs of the eleven. For skill and communication, it was set at 90% because same attributes were regularly assessed during supervision.

Because of the small number of CHWs involved in this study, the summary measures used were medians and interquartile range (IQR), and statistical comparisons between groups were made using non-parametric test like the Wilcoxon rank-sum (Mann–Whitney) test.

Ethical issues

The CHWs and the mothers participating in the role-plays were informed about the study, and written informed consent was obtained before recruitment. The study was approved by the Makerere University School of Public Health's Institutional Review Board and the Uganda National Council of Science and Technology.

Results

Characteristics of community health workers

A total of 57 CHWs were assessed, of which 40 (70%) were females. The mean age was 38 years (SD 7.6). Forty-nine (86%) had completed over 7 years of formal education. Thirty-nine (68%) had worked as community resource persons prior to joining UNEST mainly as members of their respective village committees (24/57, 42%). Over a period of 25 months, CHW referred between 0 and 60 newborns. Other CHWs' characteristics are summarised in Table 2.

Knowledge of newborn danger signs

The minimum knowledge score attained by the CHWs was 14 of the expected maximum of 16 (88%), with a median of 16 (100%). Forty-two of the 57 CHWs (74%) mentioned all five newborn danger signs unprompted. The most commonly mentioned newborn danger signs were red umbilicus/cord with pus (100%), newborn feeling hot or cold (83%), failure to breastfeed (77%) and convulsions (63%). None of the CHWs mentioned chest in-drawing and grunting as newborn danger signs (Table 3). Almost all of the CHWs (56, 98%) correctly identified all the prompted newborn danger signs. 68% attained the pass mark for knowledge and the median score was 100% (IQR 94%–100%). Overall, there was no significant difference in the median score: by sex, district of work, level of education and age of CHWs.

Table 2 Background characteristics of the community health workers

Characteristics	Categories	N = 57 n (%)
District of operation	Iganga	44 (77.2)
	Mayuge	13 (22.8)
Location	Urban	17 (29.8)
	Rural	40 (70.2)
Gender	Male	17 (29.8)
	Female	40 (70.2)
Marital status	Never married	2 (3.5)
	Married	49 (86.0)
	Widowed	3 (5.3)
	Divorced/separated	3 (5.3)
Education	Primary	8 (14.0)
	Post-primary (s1–s6) and above	49 (86.0)
Ethnicity	Musoga	50 (87.7)
	Others	7 (12.3)
Occupation	Peasant farmer	39 (69.6)
	Business person	8 (14.3)
	Civil servant	5 (8.9)
	Others	4 (7.2)
Worked as community resource person prior to UNEST	Yes	39 (68.4)
	No	18 (31.6)

Table 3 Newborn danger signs mentioned by community health workers (unprompted)

Newborn danger sign	Frequency (%)
Red umbilicus/cord with pus	57 (100)
Newborn feeling hot or cold	47 (83)
Failure to breastfeed	44 (77)
Convulsions	36 (63)
Rapid breathing	28 (49)
Lack of body movement when stimulated	23 (40)
Preterm birth	15 (26)
Yellowing of the soles/palm	10 (18)
More than 10 skin pustule	9 (16)
Chest in-drawing	0 (0)
Grunting	0 (0)

Ability to identify newborn danger signs

The minimum score on ability to identify newborn danger signs attained by the CHWs was 7 of the expected maximum of 11 (74%), with a median of 10 (91%) and an IQR of 82%–100%. 98% correctly identified all four newborn case-vignettes as either sick or not sick. 'Preterm birth' was the least identified danger sign from the case-vignettes by only 51% (Tables 4). All CHWs correctly described the appropriate action to be taken for the sick newborn case-vignettes and 89% for the healthy newborn. 63% of the CHWs scored the pass mark of 90%. The median scores by the CHWs differed significantly between district of work (Iganga = 91%, Mayuge = 82%, $P < 0.001$).

Effective communication by CHWs to mothers of the newborns

The minimum score attained on communication by the CHWs was 14 of the expected maximum of 18 (78%), with a median of 17 (94%). Overall, 63% scored the pass mark of 90%. However, only 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 had a danger sign, demonstrated by all CHWs. The poorest demonstrated attribute was that of clearly explaining to the mothers that they needed to keep the newborn warm and continue breastfeeding while being taken for referral care, which was demonstrated by only 17 CHWs (30%) (Table 5).

96% completed all the referral form variables correctly, and 63% scored the pass mark of 90%. The median score was 94% (IQR 89%–94%). The median scores of the CHW differed significantly by district of work (Iganga = 94%, Mayuge = 83%, $P < 0.001$).

Discussion

In this study, the CHWs demonstrated a high level of competence on knowledge of newborn danger signs, ability to identify sick newborns with danger signs, and effectively communicating to mothers the need to immediately seek care for their sick newborns from health facilities.

We found that trained CHWs are able to retain adequate knowledge on newborn danger signs, because

Table 4 Community health workers who correctly identified case-vignettes and newborn danger signs

Newborn Danger sign	CHW correctly identifying case as sick or not n (%)	CHW correctly identifying specific danger sign in case-vignette n (%)	CHW recommending correct action for the newborn
Case-vignette 1 - sick	57 (100)	–	57 (100%)
Failure to suckle	–	42 (74)	–
Smelly fluid oozing out of cord	–	57 (100)	–
Skin pustules	–	54 (95)	–
Case-vignette 2 - Not sick	53 (92.9)	*	51 (89%)
Case-vignette 3 - Sick	57 (100)	–	57 (100%)
Feeling hot	–	34 (60)	–
Baby's neck and limb stiff	–	36 (63)	–
Very pale	–	35 (61)	–
Preterm birth	–	29 (51)	–
Case-vignette 4- Sick	56 (98.3)	–	57 (100%)
No power in the limbs	–	52 (91)	–
Difficulty in breathing	–	50 (88)	–
Feels cold	–	47 (83)	–

*No danger sign in this case-vignette.

Table 5 Communication attributes fulfilled by community health workers during role-plays

Communication attributes	Yes *n* (%)
Informing the mother that the newborn needs to be referred to the health facility	57 (100)
Clear explanation of purpose of the visit	56 (98)
Greeting the mother	55 (97)
Clear explanation for the referral	55 (97)
Mentioning clearly place to go to for referral care	53 (93)
Examination of the newborn	51 (90)
Mentioning clearly when to go for referral care	50 (88)
Introduction to mother	49 (86)
Request to examine the newborn	49 (86)
Clearly explain to the mother that they need to keep the newborn warm and continue breastfeeding while being taken for referral care	17 (30)

almost all of them correctly identified the prompted newborn danger signs (98%) and 74% mentioned the required five newborn danger signs unprompted. Kayemba *et al.* (2012) elicited similar findings in western Uganda, where 87% of the village health team members could mention 3 and more of the newborn danger signs with infected umbilical cord (81%) as the most commonly mentioned danger sign under the integrated community case management programme (Kayemba *et al.* 2012). In a similar assessment in Pakistan, lady health workers obtained a median knowledge score of 65% regarding newborn care, with the minimum score set at 50% (Ariff *et al.* 2010). However in our study, grunting and chest in-drawing were not mentioned by any of the CHWs. This is probably because they were not highlighted during the CHWs' training, as they are less obvious in newborns, but emphasis was put on 'difficulty in breathing' among the respiratory danger signs. Further, preterm birth was among the least mentioned newborn danger sign (26%), yet it is the first leading cause of death among newborns (Oestergaard *et al.* 2011) and of high public health importance in Uganda (WHO 2006). With 14 800 babies dying annually due to preterm complications, Uganda is one of the countries with a highest burden of preterm babies, in 12th position globally. It is also 13th among the 15 countries contributing to two-thirds of global preterm births (WHO *et al.* 2012).

Our study demonstrates that trained CHWs are able to attain high levels of relevant skills to identify sick newborns in their communities. 98% of the CHWs correctly classified newborn case-vignettes as either sick or not sick. The high level of skills demonstrated by the CHWs was probably due to the regular and innovative model of supervision that involved direct observation and debriefing of the CHWs during home visits, and monthly

meetings between CHWs and the health workers (supervisors) (Waiswa *et al.* 2012). This model of supervisory approach most likely reinforced the CHWs' ability to retain knowledge and skills in newborn care. Waiswa *et al.* (2010a) also found that CHWs were able to perform roles related to the training they received on breastfeeding, malaria prevention, family planning, safe motherhood, among others (Waiswa *et al.* 2010b). Likewise, Gill *et al.* (2011) demonstrated that trained traditional birth attendants can manage perinatal conditions and significantly reduce neonatal mortality in rural African setting. But generally, not many studies have been carried out to assess the skills of CHWs in identifying sick newborns, although similar work has been carried out among older children (Kallander *et al.* 2006; Khanal *et al.* 2011; Mukanga *et al.* 2011) and for other cadre of health workers (Kolstad *et al.* 1997).

CHWs participating in this study also demonstrated that they can effectively communicate with mothers about the need to seek care for their sick newborns from health facilities, and that they can appropriately refer them to the health facilities as reflected by the overall median score of 94% on the attributes assessed. Effective communication by healthcare workers is a critical component during provision of health care (Agrawal *et al.* 2012), and our study adds to the growing body of evidence that trained CHWs can effectively contribute to healthcare delivery at community level. The continuous regular support supervision offered to the CHWs during the implementation of the UNEST intervention could also have contributed in enhancing communication skills of the CHWs. The differences in the median scores between district of work of the CHWs, in the skill and communication components could have been due to possible differences in the intensity of supervision given that Mayuge has less health facilities, hence a bigger ratio of 1 supervisor to at least 9 CHWs, compared to Iganga, where the ratio was 1 supervisor to at most 5 CHWs. Supervision time could also have been lessened by the long distances the supervisors had to cover.

Methodological issues

Ideally, the CHWs' ability to identify newborn danger signs should have been assessed using actual sick newborns because the case-vignettes used may not have adequately depicted newborn danger signs. 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. Our findings might have been different with actual sick newborns. Secondly, CHWs from one

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area were studied, which limits generalisation of our findings and necessitates larger studies. Despite these limitations, we believe that our findings generally reflect CHWs' ability to effectively identify and refer sick newborns in this setting.

This study in sub-Saharan Africa (SSA) has demonstrated that regularly supervised and trained CHWs in rural settings with a poor health systems are able to maintain a high level of knowledge on newborn danger signs and are competent in identifying and referring sick newborns to health facilities. Previous studies among CHWs in SSA have examined CHWs' ability to manage older children (Gouws *et al.* 2005; Kallander *et al.* 2006). Our study adds to the evidence from Asia (Bang *et al.* 1999; Baqui *et al.* 2008; Kumar *et al.* 2008; Darmstadt *et al.* 2010) that CHWs can contribute to strengthening the supply side of the health system, by conducting home-based programmes to improve newborn health. Our findings also support earlier evidence that simple tasks can be shifted to CHWs (Kinney *et al.* 2010) to increase coverage of essential interventions for child survival (Haines *et al.* 2007; Khanal *et al.* 2011; Mukanga *et al.* 2011). Thus, countries in a similar context, constrained by human health resources and implementing home visits for newborns, can consider using CHWs. However, mothers' adherence to the referral advice and sustainability issues regarding long-term facilitation of CHWs requires further research.

Uganda is rolling out utilisation of CHWs as part of an effort towards improving newborn survival, and there are lessons to learn from our study, such as training CHWs before assigning them tasks, regular supervision and regular debriefing after home visits. This approach enhances knowledge and skills acquisition and improves communication skills. Preterm birth as a danger sign and its role in newborn mortality should be highlighted during the training and supervision. Overall, CHWs are a potential resource that can be utilised in settings constrained with human resource for health, in the identification and referral of sick newborns to improve child survival.

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PLOS ONE

High Compliance with Newborn Community-to-Facility Referral in Eastern Uganda:.An Opportunity to Improve Newborn Survival

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Abstract

Background: Seventy-five percent of newborn deaths happen in the first-week of life, with the highest risk of death in the first 24-hours after birth.WHO and UNICEF recommend home-visits for babies in the first-week of life to assess for danger-signs and counsel caretakers for immediate referral of sick newborns. We assessed timely compliance with newborn referrals made by community-health workers (CHWs), and its determinants in Iganga and Mayuge Districts in rural eastern Uganda.

Methods: A historical cohort study design was used to retrospectively follow up newborns referred to health facilities between September 2009 and August 2011. Timely compliance was defined as caretakers of newborns complying with CHWs' referral advice within 24-hours.

Results: A total of 724 newborns were referred by CHWs of whom 700 were successfully traced. Of the 700 newborns, 373 (53%) were referred for immunization and postnatal-care, and 327 (47%) because of a danger-sign. Overall, 439 (63%) complied, and of the 327 sick newborns, 243 (74%) caretakers complied with the referrals. Predictors of referral compliance were; the newborn being sick at the time of referral- Adjusted Odds Ratio (AOR) = 2.3, and 95% Confidence-Interval (CI) of [1.6 - 3.5]), the 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 (25-29) and (30-34) years, (AOR =0.4; 95% CI: [0.2 - 0.8]) and (AOR = 0.4; 95% CI: [0.2 - 0.8]) respectively.

Conclusion: Caretakers' newborn referral compliance was high in this setting. The newborn being sick, being born to a younger mother and a reminder visit by the CHW to a referred newborn were predictors of newborn referral compliance. Integration of CHWs into maternal and newborn care programs has the potential to increase care seeking for newborns, which may contribute to reduction of newborn mortality.

Introduction

The prevailing high levels of newborn deaths are a major barrier to the achievement of the fourth millennium development goal (MDG-4) particularly in Sub Saharan Africa (SSA) where the risk of death during the neonatal period is highest [1]. MDG-4 aims at reducing child mortality levels of 1990, by two thirds by 2015. Globally, 43% of child deaths are of newborns [1], with 99% of them occurring in low income countries (LICs) and most die at home [2,3]. In Uganda, the Neonatal Mortality Rate (NMR) is 27.0 deaths per 1000 live births [4], compared to 35.9 in Africa [2].

Globally, the leading causes of newborn deaths are complications from preterm births (29%), asphyxia (23%) and infections due to sepsis and pneumonia (25%) [5]. Other causes include delays to get health care for sick newborns. In

Uganda, Waiswa et al., demonstrated that newborn deaths are mainly due to delays in; recognizing the illness and making decision to seek care (50%), reaching a health facility (20%), and receiving quality care at the health service point (30%) [6].

Newborn referral from communities to health facilities is a strategy that has been shown to improve newborn survival in south Asia [7,8]. Community newborn referrals can be initiated by community health workers (CHWs) [9,10,11,12], traditional birth attendants (TBAs) [13], or self-referrals [11]. However, for newborns to benefit from the referrals, their caretakers (mothers or guardians) should comply with referral advice in a timely manner to increase chances of survival.

In Uganda, the level of and the determinants of compliance with newborn referral are not known. Existing data focus on older children aged 1- 59 months. For instance, under the Integrated Management of Child Illnesses strategy, compliance with referral from health centres to district hospitals among under-fives and children aged one week to 2 months was 28% and 21%, respectively. In another study focusing on home-based management of fever program, compliance with community drug distributors' referral advice from community to health facilities, was 93% among under-five children [14,15]. In south Asia, compliance to newborn referrals facilitated by CHWs was reported to range between 30 - 54% [16,17], suggesting existence of substantial barriers to newborn care seeking.

Therefore a critical knowledge gap exists about newborn referral compliance and its determinants in SSA. Hence, this study evaluated timely compliance with newborn referrals initiated by CHWs, and its determinants in eastern Uganda.

Materials and Methods

Study setting

This study was conducted between June and July 2012 at the Iganga-Mayuge Health Demographic Surveillance Site (HDSS) [18] located 78 kilometres (km) east of Kampala, the capital city of Uganda. The HDSS has about 70,000 people, living in 65 villages, of which 13 are peri-urban forming Iganga town council and the rest are rural. The majority of the population practice subsistence farming for a living. Over half of the population (56%) are below 18 years of age. Only 57% of all child births occur at health facilities [4]. This study was conducted as an add-on to the Uganda Newborn Survival Study (UNEST) within the HDSS, details of which are described elsewhere [19]. The UNEST provided a good opportunity to evaluate compliance with newborn referrals initiated by CHWs.

Study design and population

A historical cohort study design was used. Registers maintained by the CHWs under the UNEST were reviewed to identify newborns that were referred to health facilities between September 2009 and August 2011. All newborns referred during this period were eligible for inclusion in this study. Location details recorded on the referral forms were used to trace the caretakers of identified newborns in the community for interview.

During the conduct of the UNEST, a CHW referred either a sick newborn for appropriate care, or a newborn delivered outside a health facility for immunisation and postnatal care. Since the first day of life bears the highest risk of death for newborns, CHWs were trained to counsel all caretakers with referred newborns to comply with the referral immediately. CHWs were also required to make a follow up visit to the referred newborns as a reminder to comply with the referral within 24-hours. A sick newborn was defined as one identified by the CHW to exhibit one or more of the newborn danger signs adopted from the WHO-UNICEF algorithm. The newborn danger signs included; difficulty in breathing, fever, coldness, yellowing of eyes and body, severe skin rash with pus, diarrhoea, vomiting excessive crying, very weak, failure to breastfeed, convulsions and an umbilical cord with pus or redness [20].

The CHWs completed a referral form for each newborn they referred. The form indicated the village, parish and sub county of residence , names of the newborn, mother and head of household, age and dates of birth and referral of the newborn, reason for referral, in addition to the name of the referring CHW.

A team of the Iganga-Mayuge HDSS research assistants was trained on the objectives and study tools of this study for three days, including one day of pre-testing. During data collection, the completed referral forms served two purposes; i) they provided some data (to minimise recall bias by caretakers) and ii) they acted as guiding tools to trace the households of identified newborns in the community. On successful tracing of the household of the identified newborn, the study objectives were explained to the caretaker of the newborn (identified as the person in the household who provided most of the day-to-day care to the newborn), and written informed consent sought.

The study questionnaire was then administered to the caretaker. The questionnaire collected data including; i) demographics of the caretaker at the time of referral, ii) date and age of the newborn at referral iii) reason for referral of the newborn (ii and iii were obtained from the referral forms), 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) compliance with referral advice given by CHW, viii) reason(s) for non-compliance, ix) follow up visit to referred newborn by CHW, x) 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 tools used in UNEST.

Statistical analysis strategy

Double data entry was done using the EPIDATA statistical package. Data were cleaned and exported to STATA statistical package version 10 for analysis. Univariate statistics were used to describe the characteristics of the newborns and their caretakers. Further, proportions of the caretakers who complied with the newborn referral were calculated, using all newborns enrolled in this study as the denominator. Referral compliance in this study was defined as a health facility visit by

the newborn caretaker 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. The 24-hour time frame was selected given that the highest risk of newborn death is within this period of life [21]. Since compliance is also influenced by several factors, a 24-hour period was deemed realistic for the caretakers to respond positively. Other authors have also defined delay in compliance with newborn referral using the same timeline [15,17].

To classify the SES of households, principal component analysis (PCA) was run on 12 household assets evaluated. These assets included; i) source of drinking water mostly used, ii) toilet facility used, iii) type of housing, iv) number of rooms, v) material of floor, roof, and walls of the house, vi) Type of cooking fuel, vii) lighting source, viii) tenure of the house ix) ownership of any of the following: cattle, sheep, goat, pig or chicken, x) ownership of land, xi) number of cooked meals consumed in day, and xii) ownership of any of the following: bicycle, motorcycle, radio, table, bed, mosquito net, CD player, mobile phone, television set or farm implements. The principal component on which most assets loaded (the first principal component) was used to generate an SES score for each newborn's household. The households were then grouped into five descending SES quintiles, with higher quintile indicating higher SES. This approach has also been used in Demographic and Health Surveys in Uganda [4], and Mayega et al [22].

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. Before conducting multivariable analysis, we investigated existence of multicolinearlity using the correlation coefficient between each pair of the independent variables. If any two variables were found to have a correlation coefficient value greater than 0.5 with a p-value less or equal to 0.05, one of them was excluded in the multivariable analysis logistic regression analysis, retaining the one with a higher p-value in the model. All the remaining independent variables initially included in the logistic regression model. One was removed at a time, starting with the variable with the highest p-value, until a final model was obtained containing only variables with a p-value less or equal to 0.05. The independent factors investigated included; i) demographic and background characteristics of the caretakers, heads of households and newborns ii) place of delivery of referred newborn, iii) reason for newborn referral, iv) SES of the household, v) newborn symptoms present at referral including difficulty in breathing, yellow eyes and body severe skin rash with pus, excessive crying, and newborn being very weak difficulty in breastfeeding; vi) caretaker's perception of health condition of the newborn, and xiii) CHWs going back to check on referred newborns shortly after referral.

The Hosmer-Lemeshow test was used to assess the goodness of fit of the logistic regression model. The final model had a Hosmer-Lemeshow test p-value of greater than 0.05, which was considered an adequate fit to the data [23]. We report crude odd ratios (COR) and adjusted odd ratios (AOR) with their respective 95% confidence intervals (CI) and p-values as measures of association.

Ethical statement

The study protocol was approved by the Makerere University, College of Health Sciences, School of Public Health Higher Degrees Research Committee and the National Council of Science and Technology (Ref. SS2660). Written informed consent was sought from all study participants prior to the interviews and confidentiality observed by use of identification numbers for the respondents. Permission was also sought from the Iganga-Mayuge HDSS management. Data from this study is available on request with justification from the corresponding author of this article.

Results

Background characteristics of the caretakers and newborns

A total of 724 newborns were referred by the CHW between September 2009 and August 2011; of which 700 were successfully traced and all of their caretakers consented to participate in this study. Caretakers of 24 newborns were reported to have changed residence to unknown addresses. A total of 689 of the 700 respondents (98%) were mothers to the newborns, with a mean age of 27 years (SD 6.4 years). The majority of the caretakers 648 (93%) were currently married. Of the 631 caretakers who reported to have ever attended school, 46% had completed 7 years of formal education. Of the 700 newborns, 51% were males, and 56% were delivered at a health facility. The rest of the characteristics are presented in Table 1.

Of the 700 newborns, 87% were referred during the first week of life at a median age of 3 days (range 2-7). A total of 373 (53%) were referred for immunisation and postnatal care, and the rest referred due to sickness. Among those referred due to sickness, the most common symptoms reported included; fever (69%), difficulty in breathing (29%), difficulty in breastfeeding (14%), excessive crying (11%), and an umbilical cord with pus or bleeding (10%) (Figure 1).

Newborn Referral Compliance

Of the 700 newborns referred, 640 caretakers (91%) had sought referral care, regardless of the time taken, with a median time of 16 hours (range 3-48). However, 439 (63%) of the caretakers had complied with the referral advice within 24-hours, with a median time of 13 hours (range 2-17). Out of 327 newborns referred due to sickness, 243 (74%) caretakers complied within 24-hours compared to 196 of the 373 (53%) referred for immunisation and postnatal care (p<0.001) (Table 2).

Among the 261 caretakers who did not comply with the referral advice, 60 (23%) did not seek referral care at all, while the rest 201 (77%) sought care after 24-hours. Of the 60 caretakers who did not seek care at all, 39 (65%) were those whose newborns were referred due to sickness.
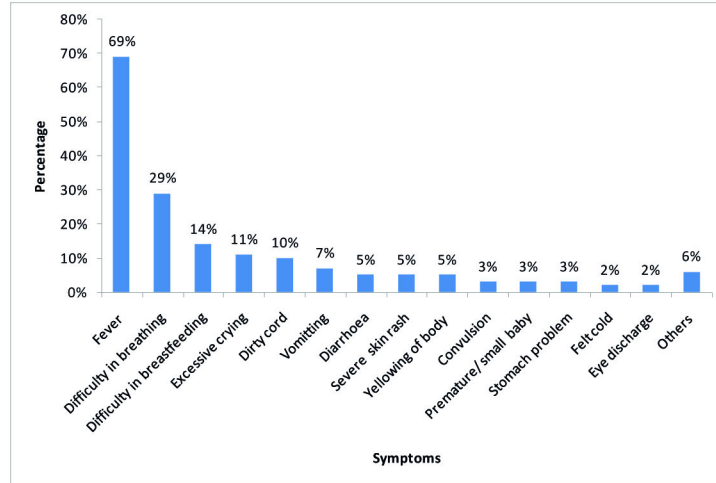
Figure 1. Symptoms reported by caretakers of newborns referred due to sickness.

Table 1. Background characteristics of caretakers and newborns.

Characteristics	Category	Freq (N=700)	Percentage %
Caretakers			
Age of mother of newborn§	<20	53	8.6
	20 - 24	178	28.9
	25 - 29	153	24.9
	30 - 34	141	22.9
	35 - 39	55	8.9
	40+	35	5.7
Marital status of caretaker	Never married	21	3.0
	Currently married	648	92.6
	Widowed	6	0.8
	Divorced /separated	25	3.6
Relationship of caretaker to newborn	Mother	689	98.4
	Other	11	1.6
Ethnicity of caretaker	Musoga	565	80.7
	Others	135	19.3
Caretaker ever attended school	Yes	631	90.1
	No	69	9.9
Years of formal education completed by caretaker	<7(Primary education)	288	45.6
	≥7(Post primary)	343	54.4
Newborns			
Sex of newborn	Male	342	48.8
	Female	359	51.2
Age of newborn at referral	≤7 days	607	86.7
	>7 days	93	13.3
Place of birth of newborn	At facility	389	55.7
	Outside facility	311	41.3

§ N=615

Table 2. Compliance rates with newborn referral by selected characteristics of newborns and caretakers.

Characteristic	Group	n	Complied with 24 hours	Did not Comply with 24 hours	p-value
Age of newborn at referral	1 wk	607	374 (61.6)	233 (38.4)	
	> 1 wk	93	65 (69.9)	28 (30.1)	0.125
Reason for referral	Sick	327	243 (74.3)	84 (25.7)	
	Immunisation	373	196 (52.6)	177 (47.5)	<0.001 *
Place of delivery	Facility	389	260 (66.8)	129 (33.2)	
	Outside facility	311	179 (57.6)	132 (42.4)	0.012*
CHW visits in pregnancy	<3 times	591	370 (62.6)	221 (37.4)	
	≥3 times	109	69 (63.3)	40 (36.7)	0.890
CHW visits after delivery	<3 times	648	408 (63.3)	240 (37.0)	
	≥3 times	52	31 (59.6)	21 (40.4)	0.631
Reminder visit by CHW	No	153	78 (51.0)	75 (49.0)	
	Yes	533	353 (66.2)	180 (33.8)	0.001*
Wealth quintiles (Poor to least poor)	1st	135	79(58.5)	56 (41.5)	
	2nd	135	85(63.0)	50 (37.0)	0.455
	3rd	135	90 (66.7)	45 (33.3)	0.167
	4th	135	80(59.3)	55 (40.7)	0.902
	5th	135	88(65.1)	47 (34.8)	0.260

* Statistically significant <0.05

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. The most common means of transport to seek referral care from the health facilities was "walking,"

Table 3. Barriers for timely compliance reported by caretakers of referred newborns by reason for referral.

Reason for non- compliance	Sick	Immunisation	Overall
	(n=84)	(n=177)	(N=261)
	Freq (%)	Freq (%)	Freq (%)
Mother sick	14 (16.7)	36 (20.3)	50 (19.2)
Waiting for immunisation outreach	2 (2.4)	43 (24.3)	45 (17.2)
Waiting for umbilical cord to drop off	3 (3.6)	36 (24.3)	39 (14.9)
Lack of Transport	12 (14.3)	10 (5.7)	22 (8.4)
Health workers absent during weekend	5 (6.0)	5 (2.8)	10 (3.8)
CHW advised mother to go after 1 week	1(1.2)	6 (3.4)	7 (2.7)
Bad weather	4 (4.8)	1 (0.6)	5 (1.9)
Mother busy with work at home	2 (2.4)	3 (1.7)	5 (1.9)
Long distance to facility	0 (0.0)	3 (1.7)	3 (1.2)
Had sick person at home	0 (0.0)	3 (1.7)	3 (1.2)
Needed permission from husband	1 (1.2)	2 (1.2)	3 (1.2)
Others	8 (9.5)	8 (4.5)	16 (9.0)

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used by 47% (301/640) of the caretakers. The mean distance from the caretakers' residence to the health facility where referral care was sought was 2 km (SD1.6).

Out of the 39 sick newborns whose caretakers did not seek referral care at all, 27 (68%) were treated at home. The caretakers treated these sick newborns either with medicines newly bought 21 (54%), or with old-stock drugs kept at home 6 (15%).

Reasons for non-compliance

Caretakers who did not comply (261) mentioned several reasons for non –compliance. Fifty (19%) of the caretakers did not comply because "the mother was sick (unwell)", 45 (17%) caretakers were "waiting for an immunization outreach" services in their area, and 39 (15%) were "waiting for the newborn's umbilical cord to drop off". A summary of the rest of the reasons is presented in Table 3.

Factors associated with newborn referral compliance

Age of the mother, reason for referral of newborn and a reminder visit to the referred newborn by CHW within 24-hours were the factors found to be significantly associated with compliance with referral advice given by CHWs.

Mothers aged (25-29 and 30-34) years were both 0.4 times less likely to comply with newborn referral advice compared to younger mothers aged less than 20 years; Adjusted Odd Ratio (AOR) = 0.4; and 95% Confidence Interval (CI) of [0.2 - 0.8]) and (AOR = 0.4; 95% CI: [0.2 - 0.8]) respectively. Newborns referred because they were sick (suffered a danger sign) were 2.3 times more likely to comply with the referral advice compared to those who were referred for immunization and postnatal care; (AOR 2.3; 95% CI: [1.6 - 3.5]). However, no specific danger sign was associated with compliance with referral advice. Caretakers who received a reminder visit by the CHW within 24-hours following initial referral advice were 1.7 times more likely to comply with the referral advice compared

Table 4. Multi- variable regression 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	Immunisation	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]

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to those who did not receive such a visit; (AOR 1.7; 95% CI: [1.2 - 2.7]). The rest of the results are summarized in Table 4.

The other factors assessed but were found not to be significantly associated with compliance with referral advice included; marital status and educational status of caretaker, age of head of household, social economic status of household, sex of newborn and his/her birth order at referral, place of delivery, number of times CHW visited caretaker before and after delivery, and symptoms exhibited by the newborn at time of referral, including; difficulty in breathing, fever, feeling cold, yellowing of body, severe skin rash, vomiting , excessive crying , dirty cord, diarrhea, low birth weight, and difficulty in breastfeeding. These are not included in the Table 4.

Discussion

This study is one of the few that report newborn referral compliance in SSA. We report compliance within 24-hours, with community to health facility referral by CHWs for both sick and healthy newborns unlike other authors who focused on only sick newborns [17,24,25,26]. The factors (age of mother, health status of newborn at referral and a reminder visit by a CHW) that were significantly associated with newborn compliance differed from those documented in studies done in south Asia.

The findings of this study support the evidence of the positive role CHWs can play in enhancing newborn care seeking in rural Uganda and other similar settings.

Compliance with newborn referral and role of community health workers

We found a relatively high level of timely newborn referral compliance for both sick (74%) and healthy newborns referred for immunisation and postnatal care (53%), respectively. Referral of healthy newborns for immunisation and postnatal care was of interest because many of them are born outside facilities in this setting [4]. Attending postnatal care gives a chance to identify and treat newborns that may exhibit a danger sign including congenital abnormalities that may have been missed by CHWs.

Ninety-one percent of the caretakers completed referral regardless of the time taken to seek for referral care, similar to the completion rate of 87-95% reported by Nsibande et al., in South Africa [25] and higher than 86% compliance rate reported by Kirkwood et al., in Ghana [26]. Our study found a higher compliance rate of 74% among sick newborns compared to that found by Darmstadt et al., of 54% and by Baqui et al., of 32% among similar newborns referred by CHWs in southern Asia [17,24].

The higher level of compliance we found could have been due to the health system strengthening and regular meetings between CHWs and health workers conducted during the UNEST intervention which probably increased the communities' trust in health facilities. The health system strengthening was done through training and reinforcing health workers' knowledge and skills in newborn care and providing some resuscitation equipment like ambubags and masks, nasal gastric tubes, drugs such as gentamycin and injection ampicillin to treat newborn infections.

Further, the higher level of compliance with CHW referrals in our study could also be attributed to the several interactions made between the mothers and the CHWs before and after delivery as part of the UNEST intervention activities [19]. During antenatal visits, mothers are encouraged to deliver in health facilities and to immediately seek care from health facilities whenever they recognise maternal and newborn dangers signs. The same messages were re-echoed during the postnatal home visits made by the CHWs. Further, over 95% of pregnant mothers in this setting attend at least one facility based antenatal visit before delivery [4], during which similar messages are emphasized. All this could have contributed to promote compliance with community newborn referrals. These findings support existing evidence regarding the significant role CHWs can play in promoting compliance with newborn referrals [11,26,27].

Factors associated with newborn referral compliance

Older mothers (25-34 years) were less likely to comply with newborn referral possibly because they are more familiar and have experience with newborns compared to young mothers who are likely to be first time mothers. Together with the increasing responsibilities as one gets more children, these factors could prevent the older mothers from complying with newborn referrals. Whereas we found age of the mother to be associated with compliance with referral, Darmstadt et al., 2010 did not do so [17].

We also found that health status of the newborn at the time of referral was a significant determinant of compliance by the caretakers. Although we did not assess severity of symptoms of sickness, it is possible that caretakers responded depending on the perceived severity of symptoms of the sickness, such that caretakers of newborns referred for immunization and postnatal care were less motivated to comply with referral advice since the babies were presumably health. Previous studies have also found severity of symptoms of sickness to be associated with newborn referral compliance [12,17]. Similarly, health status of a child was associated with compliance with referral from community to health facilities among children aged below five. Those categorised as 'urgent for referral' were more likely to access referral care than those in the non urgent category (p=0.016) [15].

A reminder visit by CHWs to referred newborns within 24 hours after counselling the caretaker to seek referral care was significantly associated with timely compliance. A follow-up visit to a sick newborn was one of the activities emphasized to CHWs during their training. The reminder visit possibly achieved two purposes; first, as a reminder to the caretaker to seek referral care for the newborn, and secondly as an emphasis to the caretaker regarding the importance of seeking referral care for the newborn survival. This finding reflects the importance and contribution of CHWs in the implementation of newborn survival strategies in this setting. It also adds to the existing body of evidence that CHWs can play an important role in the promotion of newborn health [7,13,17,28,29,30]. Therefore, there is need to emphasise reminder visits to sick newborns in the CHW training guidelines.

Darmstadt et al., found that mothers of newborns aged 0-6 days were 30% less likely to comply with referral than those of older newborns [17].However, in our study, age of the newborn, was not found to be significantly associated with newborn referral compliance. Factors that have been documented to be associated with referral compliance among older children include; severity of disease [12,17], functionality of the health system [31], knowledge and perceptions of caretakers about danger-signs in the sick child [32,33] and provision of a referral slip by health workers [34].

Methodological Consideration

The strength of our work was that we attempted to trace and study all healthy and sick newborns referred by CHWs unlike previous studies that assessed only sick newborns [17,25,28]. However, our study also had limitations; first, we attempted 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 we were unable to achieve this task. We instead used self report similar to other studies [12,14].

Secondly, we conducted the assessment after 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

Table 5. Power analysis for this study using a sample size of 700.

Proportion (%) of the sick newborns among the timely compliers	Odds ratio (OR)	Power
0.55	2.0	>99
0.50	2.0	>99
0.45	2.0	>99
0.40	2.0	>99
0.35	2.0	>99
0.30	2.0	>99
0.30	1.9	98
0.30	1.8	96
0.30	1.7	91
0.30	1.6	82
0.30	1.5	69

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CHWs gave referral advice to the caretakers. In the effort to minimise recall bias we directly picked some of the information from the referral forms. This data consisted of newborn age at referral, date of referral and reason for referral.

Also to reduce the response bias that could have occurred, we used clear, precise and short questions and avoided leading ones. We also trained the data collectors to create rapport with the respondents and enable them answer the questions freely.

Thirdly, our study included the 700 caretakers of newborns that were referred. The question that arises is whether our study had enough power to detect the factors associated with timely compliance to newborn referral. We assessed the power of this study, assuming that the most important independent variable was the newborn being sick or not, and used different values of the prevalence of sick newborns among caretakers with timely compliance and non sick children. We used the Power and Sample size software [35] to compute the power of our study. Table 5 shows a summary of our assessment, and it is clear from this table 5 that this study had a power of more than 80% to detect an odds ratio of at least 1.6, if the prevalence of sick newborns among caretakers with timely compliance was at least 33%. The prevalence of sick newborns among caretakers with timely compliance in our study was 55%.

Fourthly, this was a trial setting, where the CHWs received focused training and supervision on newborn care, so our findings may not be generalised to the general health system. We also did not assess the quality of care at the referral centres, as this was outside the scope of this study, but will be reported in a subsequent study.

Lastly, the compliance level we found could have been affected by way of measurement when we defined compliance as positively responding within 24-hours to seek referral care. 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. 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 [15,17]. Further research is recommend using qualitative methods to explore and understand social cultural factors that may influence newborn referral compliance in this setting.

Policy Implications

In Uganda, newborn care has been introduced in the integrated community case management program under which community health workers (referred to as Village Health Teams (VHTs) identify and refer sick newborns [29] As this program is rolled out in the country, there are lessons to learn from our findings including; i) CHWs can effectively make a link between community and health facility, through initiating referrals for sick and healthy newborns and ii) caretakers of the newborns can pay attention to CHWs' counseling and comply with the referral advice particularly if the CHWs are encouraged to make an extra visit to the caretakers after recommending newborn referral care. These lessons add to the previous evidence generated, showing that trained and effectively supervised CHWs can identify and refer sick newborns in a rural setting [36]. We are also in the process of generating more evidence on the health facility readiness to manage sick newborns in the same setting.

Conclusion

Compliance of caretakers with community-to-facility newborn referrals initiated by CHWs was high in this setting. Acute illness, being born to a younger mother and a reminder visit by the CHW to a referred newborn were predictors of compliance with newborn referral in this study. In similar contexts integration of CHWs into maternal and newborn care programs has the potential to increase health facility based care seeking for newborns that may contribute to reduction of newborn mortality.

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Author Contributions

Conceived and designed the experiments: CKN PW JK GT SP DG. Performed the experiments: CKN PW JK GN SN GT SP DG. Analyzed the data: CKN PW JK GN SN GT SP DG. Contributed reagents/materials/analysis tools: CKN PW JK GT SP. Wrote the manuscript: CKN PW JK GN SN GT SP DG. Drafted first manuscript version which was later improved on by all the authors: CKN.

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Title

Health system preparedness for newborn care: A health facility assessment in rural Uganda.

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ABSTRACT

Background: Health facilities have a critical role to play in saving the 2.9 million newborns at risk of dying every year worldwide. There is a dearth of data on the capacity of rural facilities in Uganda to care for newborns. We assessed the capacity of health facilities to care for newborns for the main mortality causes: preterm/ low birth-weight, asphyxia and infections in rural Uganda.

Methods: Between July and August 2013, we conducted a cross-sectional study among a total of 92 health-workers, and in 20 health facilities: one hospital and19 primary health care centres (1 Level IV, 6 Level III and 12 Level II) in areas where some health facility strengthening for newborn care had occurred. The indicators included; newborn services offered, equipment, drugs, supplies, documentation, trained staff, supervision, and health-workers' knowledge and skills.Analysis was done using STATA version 10 and availability scores computed.

Results: Fifteen of the 20 health facilities offered newborn care. Level II facilities had the lowest availability score for resuscitation equipment (31%) compared to the hospital/level IV (71%) and level III (74%) facilities. None of the level II facilities offered kangaroo mother care 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. Availability score for newborn sepsis drugs was 8%, 67% and 75% for levels II, III and the hospital/ level IV, respectively. Two-thirds (33/50, 66%) of the health-workers were considered knowledgeable in newborn care, but less than a half (17/42, 41%) skilled in newborn resuscitation.

Conclusions:

Health-workers had good knowledge but modest skills for newborn care. Overall, higher level health facilities were more prepared for newborn care than the lower level facilities.The national essential drug policy should be revised to provide level II facilities with drugs that treat newborn sepsis. Health facilities that conduct deliveries should also provide good quality preterm/low birth-weight and asphyxia care, irrespective of their level.

Key words: Health facility, capacity, newborn, health-workers, knowledge, skill, Uganda.

INTRODUCTION

Forty-four percent of the childhood deaths in the world are newborn deaths [1-2] with 450 newborns dying hourly [3]. In Africa the newborn mortality rate (NMR) is 35.9 deaths per 1000 live births [1]whereas in Uganda it is 22.2 deaths per 1000 live births [4].Worldwide, the main causes of newborn deaths are preterm and low-birth-weight complications, birth asphyxia and sepsis [2-3, 5] . Unless global health programs address newborn deaths more effectively, neither Millennium Development Goal Four (MDG-4) of reducing child mortality by two-thirds by 2015 [1, 3], nor the new global target of reducing child mortality to 20 deaths per 1000 live births or less by 2035 [6-7] will be realised.

In response to improve newborn survival, many sub-Saharan African (SSA) countries are rolling out both community and facility-based interventions for newborn care. Many, including Uganda, have introduced home visits and the referral of sick newborns for facility-based care, following a recommendation by the World Health Organization (WHO) and the United Nations Children Fund (UNICEF) [8].

A cluster randomised controlled trial (ISRCTN50321130) - the Uganda Newborn Survival Study (UNEST) – was conducted between December 2008 and May 2012 – in eastern Uganda, with the aim of approving maternal and newborn outcomes, details of which have been described elsewhere [9]. UNEST used a community-based intervention to link communities and health facilities by training 61community health workers (CHWs) to conduct home visits to pregnant and newly delivered mothers. During the home visits, CHWs identified and referred sick newborns to health facilities for care and those born outside health facilities for immunisation and other postnatal care. Furthermore, UNEST conducted health facility strengthening activities to reinforce maternal and newborn care services in health facilities, as described in Figure 1.

Sub-studies conducted within UNEST [9] have shown that : i) CHWs can identify and appropriately refer newborns for facility-based care [10] and ii) caretakers of newborns largely complied with referrals to seek postnatal services, such as immunisation for healthy babies and treatment for those with danger signs [11]. However, there is a dearth of data on whether the lower-level health facilities in rural Uganda would be able to provide care to newborns referred by the CHWs. Studies conducted elsewhere in SSA have reported inadequacies in logistics for newborn care in health facilities [12-16].

This study aimed to assess the capacity of mainly lower-level health facilities to provide care for newborns in rural eastern Uganda within the context of the UNEST for the main causes of newborn mortality; preterm and low birth weight, birth asphyxia and sepsis.

METHODS

Study setting

This study was conducted within the Iganga-Mayuge Health and Demographic Surveillance Site (HDSS) [17] located 120 kilometres east of Kampala, the capital city of Uganda. The HDSS consists of 65 villages that are predominantly rural. The total population under surveillance is approximately 80,000 people, the majority (56%) being below 18 years of age. [18]. The main source of livelihood is subsistence farming, followed by small-scale retail trade.

Study design, population, tools and data collection

Between July and August 2013, we conducted a cross-sectional study to assess the capacity of 20 health facilities at different levels of primary health care to provide care to sick newborns. The health facilities selected were those targeted by UNEST for strengthening (Figure 1.) during its intervention[9]. 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-twohealth workers at these facilities also participated in face-to-face interviews. Fifty of these health workers were assessed for knowledge and 42 were assessed for newborn resuscitation skills.

Study tools

The capacity of a health facility to care for the newborn was defined as including: availability of equipment, supplies and drugs and competent health workers who are knowledgeable and skilled in newborn care. Thus, three study tools were used to collect data: a health facility checklist, a semi-structured questionnaire for knowledge assessment and a skills assessment checklist.

Health facility checklist

The health facility assessment was conducted 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). HNN is an initiative of Save the Children's Saving Newborn Lives [19]. This tool measures whether a health facility has capacity to address the main causes of newborn deaths: birth asphyxia, preterm births/ low birth weight and infections [3, 5, 20]. The indicators measured by this tool include: newborn service availability, equipment and supplies, documentation, trained staff and supervision. Although this tool has not been used in Uganda before, the indicators are similar to those outlined in the Newborn Health Implementation Framework – Standards for Newborn Health Care Services of the Ministry of Health, Uganda [21]. Furthermore, the tool was adjusted by adding items that were not captured by the tool but were listed in the framework. These included: multivitamins, vitamin K, 50% dextrose, tetracycline ointment adrenaline and phenorbabitone. The modified tool was pre-tested in a non-study health facility. Following the pre-test, some questions were rephrased and re-arranged to ensure clarity and logical flow. Elements assessed under each indicator are described in Additional file1.

In this tool, equipment and supplies were scored for availability and functionality at the service area. Availability was captured as 'observed', 'reported not seen', and 'not available', while functionality was reported as 'yes' or 'no'. An item was considered available if it was observed to be present and functional (for equipment) and not expired (for drugs). Service availability was reported as 'able to provide today', 'provided in past 3 months' and 'ever provided in facility' through the answers 'yes' or 'no'. A facility was deemed to offer the service if the interviewee reported that the service could be offered on the day of data

collection. Health workers' training in newborn services was scored as 'trained within past 12 months', 'trained over 12 months ago', and 'no training'. Health workers were asked when they last received a supervision session; that is, in the previous three months, in the previous 6 to 12 months, more than 12 months ago and whether the supervision included observation during the provision of any form of newborn care. A health worker was considered trained or supervised if s/he had been trained in the previous 12 months or supervised in the previous three months respectively by answering 'yes' or 'no'. The tool was administered through face-to-face interviews to the person in-charge of the health facility and the staff on duty.

Semi-structured questionnaire to assess health workers' knowledge

Health workers were assessed on knowledge of newborn care using a tool adapted from UNEST training materials. The tool consisted of three components about essential newborn care services, 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 choice questions. All questions were weighted equally. A correct answer was awarded 1 point and incorrect answer 0 point. Thus the minimum score for knowledge was 0 and maximum 64 points. This number was converted into a percentage score. Owing to a lack of national references an arbitrary pre-determined pass mark of 80% was set. This mark was set given that the questions were multiple-choice in nature so the test was considered to be relatively easy. The health workers, who attained the pass mark or more, were considered "knowledgeable", while those who obtained less than the pass mark were categorised as "not knowledgeable". The tool was pre-tested prior to data collection and administered face to face by the researchers to prevent health workers from consulting each other about theappropriate responses.

Health worker skill assessment checklist

Health workers were assessed on newborn resuscitation skills with the ambubag and mask technique on a mannequin (dummy baby). The checklist was adapted from the UNEST training materials. The checklist had four components: i) performing ten resuscitation steps scored as "done correctly" , "done incorrectly" and "not done"; ii) recognition of a successful or failed resuscitation procedure; iii) participant knowing what to do if the resuscitation was successful or not; and iv) participant knowing what to do after the resuscitation procedure was completed. The checklist was also pretested and administered face to face by the researchers.

Each item correctly done or answered was awarded 1 point; otherwise no point was awarded. All items were weighted equally. Hence the minimum score for the exercise was 0 and the maximum 23 points. Two consultant pediatricians agreed that a health worker would be considered "skilled" if he/she correctly performed: i) at least 7 out of 10 resuscitation steps (7points) and ii) was able to recognise a failed or successful resuscitation and knew the appropriate actions to take if resuscitation failed and what to do when the procedure was completed (6 points). All this translated into a pass mark of 13 points. The health workers obtaining these points or more were considered skilled in newborn resuscitation.

Data collection

Two public health specialists and three research assistants with nursing training collected data for health facility assessment and conducted interviews with health workers to assess their knowledge in newborn care. Two paediatric consultants conducted the newborn resuscitation skills assessment among the health workers. The health facilities were assessed for presence of health workers 24 hours all the seven days of the week using available duty schedules,

equipment,drugs and supplies, protocols and guidelines, forms and registers and whether the health workers were trained and supervised in newborn care.Health workers assessed for knowledge of newborn care were those on day-time duty at service areas where newborn care was likely to be offered, including: the outpatient department and the antenatal, postnatal and labour wards. 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 consultant paediatricians used a checklist and observed the health workers as they performed the resuscitation procedure on the mannequins.

Data analysis

All the data were checked for completeness and entered in the computer using EPI Data software and exported to STATA version 10 (Stata Corp, TX, USA). Proportions of health facilities with the different items (equipment, supplies, and drugs) and offering delivery and newborn care services were computed. Mean availability index and scores were computed using the Service Availability and Readiness Assessment (SARA) method, developed by the WHO for measuring health-systems readiness in service delivery [22], as used by O'Neil et al., to assess service delivery in six countries [23].

The proportions of health workers who had been trained in newborn care, those who had received supervision and those knowledgeable about newborn care were also calculated. The overall median score for each of the three knowledge areas of: preterm/low birth weight, birth asphyxia and infection were determined. Furthermore, differences in health workers' knowledge by facility ownership were examined.The proportion of health workers skilled in newborn resuscitation was computed and stratified by health worker characteristics of cadre,

and facility type. For all the analyses, the differences between groups were tested with the use of Fisher's exact test and the level of significance was considered at <0.05.

Ethical approval

Makerere University School of Public Health Higher Degrees Research Committee and the National Council of Science and Technology approved the study protocol (Ref. SS2660). All study participants were requested to give written informed consent prior to the interviews. Confidentiality was observed by use of identification numbers so that results could not be traced back to the participants. Permission was also sought from the management of Iganga–Mayuge Health and Demographic Surveillance Site.

RESULTS

Availability of newborn care services equipment, drugs, supplies, registers and protocols

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 majority (15) were government-run (public) and five were private not for profit (PNFP). Fifteen of the 20 health facilities offered newborn care and at all these facilities, a skilled provider was stated to be available 24 hours including weekend days from the available work schedules.

First level facilities (Level II) had the lowest (31%) availability score for resuscitation equipment compared to the hospital/level IV (71%) and those at level III (74%). 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. Availability score for newborn sepsis drugs was 8% for level II, 67% and 75% for

level III and the hospital/ level IV, respectively. For newborn protocols availability scores were 25%, 19% and 18% for hospital/level IV, level III and level II, respectively. Other indicators are shown in (table 1). An additional table file shows this in more detail (see Additional file 1).

Knowledge of newborn care by health workers

Of the 50 health workers assessed for knowledge of newborn care, nurses n=20, (40%) were the main profession. Eleven (22%) of the health workers knew all the definitions of a preterm and low birth weight baby, 46 (92%) correctly defined KMC and 42 (84%) correctly defined asphyxia. Forty- six (92%) correctly named eight or more newborn danger signs, preterm (low birth weight) being the least known by 36 (72%) (Table2).

Overall, 33 (66%) of the health workers, scored above the pass mark of 80%. The overall knowledge median score was (84%) (Interquartile range (IQR) 77%, 88%). 'Infection' was the most, 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 3).

Training and supervision of health workers on newborn care

Out of the 50 health workers ,42 (84%), reported to have received training in at least one of the following newborn care components within one year prior to this study: Newborn resuscitation using ambubag, 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 labor, goal oriented antenatal care, essential newborn care, and 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 levelas 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.

DISCUSSION

In this study we show that health facilities in an area with newborn intervention in rural Uganda largely had staff to provide newborn services all the time of the day. Also, health workers were generally knowledgeable in newborn care, although their skills in newborn resuscitation were unsatisfactory. Many of the health workers had received training in at least onenewborn care component and had been supervised and mentored during work. The admitting health facilities (hospital, Health Centre (HC) IV and HCIIIs) offered KMC

services, indicating that preterm and low birth weight babies could be supported. However, the health facilities had inadequate equipment, drugs and supplies, in some cases due to stock-outs or non-replacement of non-functional equipment, and in other cases by policy, such as for sepsis treatment for newborns with septicaemia in the lowest level Health Centre IIs. A few of the facilities had the protocols toguide the staff in management of newborns. Our findings add onto the existing evidencethat health facilities in SSA are inadequatelyprepared to care for newborns due to lack of essential inputs [12-16].

Uganda largely has adequate policies and guidelines to support delivery of newbornservices with one exception: drugs to treat newborn sepsis are not allowed at the first, most accessiblelevel of the formal health system which receives a majority of the sick newborns referred by CHWs to health facilities [10]. While some countries in Asia are opting for community based sepsis treatment [24-25], Uganda as many African countries opt to refer newborn with suspected septicemia to health facilities for assessment and treatment. We have earlier shown that CHWs are largely able to identify sick newborn [26], and parents take their sick newborns to the nearest facility [11] , the formal health system then proceeds to fail the sick newborns and parents on arrival, since the Uganda essential medicine list does not provide for these medicines at this level of health service delivery [27] and we consequently found them largely absent. There is need for revision of this policy to bridge this gap. We argue that, sepsis treatment needs to be available at the most accessible health facility level, which will require a policy change in Uganda. Implementation of essential care for the newborns in health facilitiesremains a challenge not just in Uganda but also in other low income countries [28].

Level II health facilities are the majority in the districts, nearest to the communities and are the first points of contact with the formal health system where communities are expected to

seek health care [29]. We have earlier shown that 77% of caretakers sought newborn referral care from public lower health facilities and only18% from the hospital [11]. Referral of sick newborns from first level health centres to hospital does not seem like a realistic alternative. Peterson et al., in their study under integrated management of childhood diseases, also demonstrated that completion of newborn referrals from lower level facilities to higher ones hardly happened, increasing the risk of death of these babies. Only two in ten of children aged 1week to 2 months completed referrals from level II facilities to hospitals for referral care, due to barriers like lack of money and transport problems [30]. Furthermore, Mbonye et al., in their analysis of newborn survival in Uganda in the last decade, echoed a similar message that the most essential treatment procedures for newborns are at a service level (HC-IV) which many families may not access [31]. Therefore, the current policy barring level II health facilities from stocking medicines like injectable gentamycin to treat newborn infections [27], should be re-evaluated to enable the health workers at this level to treat sick newborns .

We found that most of the health facilities could provide normal delivery services 24 hours, including eight levelII facilities, although at this level of service the policy stipulates only emergency deliveries.The level II facilities were providing delivery services because in some cases the district leadership operationalised them to conduct normal deliveries. In other scenarios it is because the staffing norm at level II includes a midwife whose duty is to conduct antenatal and emergency deliveries [32], but due to demand by the communities, normal deliveries are conducted. In both instances, the midwives are automatically exposed to newborns that may require resuscitation, and/or preterm and low birth weight interventions like KMC, yet the facilities are not equipped for these services. While we are not advocating that all HCIIs should conduct deliveries, we think the Ministry of Health should consider

amending policies and guidelines to provide level II facilities that conduct normal deliveries, with basic newborn resuscitation equipment and KMC.

We found that many health workers had received support supervision either internally or from district and national level, but many times the supervision was not done when the health workers were offering newborn care (hands-on), which might have contributed to inadequate skills in newborn resuscitation among two thirds of the staff. Another possible explanation for insufficient skill could be allocation of staff as described by Vesel et al., in Ghana, where staff were working at service points where their newborn resuscitation skills were not exploited, compromising the quality of newborn care offered in the health facilities [12]. Equipping and maintaining competent health workers at health facilities to address the main causes of newborn death [33], would at a larger extent enhance the progress towards achieving MDG-4 by 2015 in Uganda.

We found that there were more health workers in the public health facilities who were considered knowledgeable in newborn care than in the private facilities. This could partly be due to uneven supervision and mentorship, where emphasis has been put on the public facilities. This calls for strengthening and involvement of private health facilities in district training activities for newborn care.

As Uganda scales up community based newborn care through Village Health Teams [34], health facilities at all levels of service must at the same time be strengthened,so that they are prepared to offer care to the referred newborns. This includes providing newborn sepsis drugs to all level II facilities to treat newborn sepsis, and ensuring that wherever deliveries are conducted there is also capacity to take care of the newborn. Else empowering communities

to seek care alone, without improving the health facilitiesmay not translate into the desired reduction in newborn deaths. This was demonstrated in the NEWHINTS study in Ghana where findings showed that a community strategy of home visits and referring sick newborns to health facilities, without strengthening the latter did not result insubstantial reduction in newborn mortality [35-36].

This study was conducted in an area and health facilities that had enjoyed a newborn intervention under the Uganda Newborn Study. Possibly, this means that our findings reflect a better situation than the typical one in Uganda. However, it is evident that further improvement in formal health system capacity to care for newborns is required even beyond what was done under the UNEST intervention, and that this may require policy changes in some instances.

CONCLUSIONS

Health-workers had good knowledge but modest skills for newborn care. Overall, higher level health facilities were more prepared for newborn care than the lower level facilities. The national essential drug policy should be revised to provide level II facilities with drugs that treat newborn sepsis. Health facilities that conduct deliveries should also provide good quality preterm/low birth-weight and asphyxia care, irrespective of the level of service.

LIST OF ABBREVIATIONS

CHWs   Community health workers

HDSS   Health and Demographic Surveillance Site

HNN   Healthy Newborn Network

IMPAC   Intergrated management of Pregnancy and childbirth

IQR   Interquartile Range

MDG-4   Millennium Development Goal four

MOH   Ministry of Health

NMR   Newborn Mortality Rate

PNFP   Private not for profit

SARA   Service Availability and Readiness Assessment

Sida   Swedish International Development Cooperation Agency

SSA   sub-Saharan Africa

UNEST   Uganda Newborn Study

UNICEF   United Nations Children Fund

WHO   World Health Organisation

COMPETING INTERESTS

The authors declare that they have no competing interests. The opinions expressed in this

paper are those of the authors and do not necessarily reflect views of the funders neither the

institutions of affiliation.

AUTHORS' CONTRIBUTIONS

CKN conceived and designed the study together with DG, JK, PW, and SP. CKN, AT, NH, GN and SN collected data with supervisory guidance provided by DG ,JK, GT,PW and SP. CKN, FN, PW and SP conducted data analysis guided by DG. CKN prepared the first draft guided by GT JK, DG, PW and SP. All authors reviewed and approved the final manuscript. SP and PW contributed equally as senior authors.

ADDITIONAL MATERIAL

File name: Figure 1.

File format: Microsoft word .doc

Title of figure: Health facility strengthening by Uganda Newborn Study (UNEST)

Description of the figure: Thefigure is a brief description of the activities done during health facility strengthening as part of UNEST intervention.

File name: Additional file 1

File format: Microsoft word .doc

Title of table: Availability of services, equipment, supplies, protocols and registers /forms by health facility level.

Description of table: The table show the number of items present at the health facilities at the time of data collection and the availability scores.

Mean availability score for indicator = Sum of items present in facilities per indicator divided by the product of items per indicator and number of health facilities, multiplied by 100%.

Figure 1: Health facility strengthening by Uganda Newborn Study (UNEST)

Health facility strengthening in a district hospital and 19 lower level health facilities by Uganda Newborn Study (UNEST).
UNEST, aimed to improve maternal and newborn outcomes partly by strengthening health facilities through the following activities:

- Improve frontline health workers' competence in newborn care by conducting district-led in-service refresher training in maternal and newborn care, support supervision and mentoring.
    - The training package targeted the main causes of maternal and newborn mortality and morbidity in Uganda (preterm/ low birth weight complications, birth asphyxia and infections).
- Provided a one-off supply of essential medicines and equipment to overcome immediate critical gaps.
- Empowered health workers to utilize district resources and make requisitions for subsequent supplies.
- Re-organisation of space in the wards to cater for labor management and kangaroo mother care
- Introduction of screens in the labor ward to improve privacy of mothers.
- Re-introduced national standard files for maternal and newborn inpatient care, to improve record keeping and provide data for the audit sessions in the hospital.
- Sensitisation of district and local leaders, on the importance of maternal and newborn health.
    UNEST was a registered cluster randomised controlled trial number ISRCTN50321130

TABLES

Table1:Mean availability scores per indicator by health facility level.

Indicator	Number of items per indicator	*Mean availability score for health facilities			
		All N=20	Hospital/ Level IV N=2	Level III N=6	Level II N=12
Newborn services: KMC and Resuscitation	2	42.5%	100%	83.3%	12.5%
Newborn sepsis drugs (injectable gentamycin and ampicillin)	2	32.5%	75.0 %	67.0%	8.0%
Maternal and newborn services offered	12	47.5%	75.0%	70.8%	31.3%
Equipment and supplies	7	47.9%	71.4%	73.8%	30.9%
Infection control in delivery room	3	66.7%	66.7%	77.8%	61.1%
Space for newborn services	2	50.0%	100%	83.3%	25.0%
Equipment and supplies in postnatal area	8	15.6%	0.0%	29.2%	11.5%
Maternal and newborn drugs	13	33.8%	92.3%	65.4%	12.8%
Protocol and guideline	6	20.0%	25%	19%	18%
Register and forms	8	52.5%	62.5%	62.5	43.8%
§ Mean availability index		**39.7%.**	**57.5%**	**56.8%**	**28.3%**

*Mean availability score for indicator = Sum of items present in facilities per indicator divided by the product of items per indicatorand number of health facilities, multiplied by 100%.
§Mean availability index = Mean of mean availability score for the indicators

Table 2: Health workers with good knowledge of selected newborn care questions.

Newborn care question	Health workers N=50 n(%)
Definition of preterm baby	
Baby born less than 37 weeks of gestation	35 (70)
Definition of low birth weight	
Baby born with birth weight less than 2500g	41 (82)
Baby born above 37-42 weeks of gestation with weight of 1500g	23 (46)
Definition of Kangaroo mother care (KMC)	
Knowing correct definition of KMC	46 (92)
Definition of asphyxia	
Knowing correct definition of asphyxia	42 (84)
Newborn danger signs	
Red umbilicus or cord with pus	50 (100)
Severe chest in-drawing	50 (100)
Not breast feeding or drinking	49 (98)
Convulsion/seizures	48 (96)
Yellow soles or palms	48 (96)
Baby feel hot, or cold	45 (90)
Lack of body movement when stimulated	43 (86)
Rapid breathing in a calm child	41 (82)
Grunting	41 (82)
More than 10 (ten) skin pustules	41 (82)
Low birth weight	36 (72)
Number of correct newborn danger signs	
Knowing 8 correct newborn danger signs	46 (92)
Drugs used to treat newborn infection	
Ampicillin	50 (100)
Gentamycin	48 (96)
Knowing both Ampicillin and Gentamycin as sepsis drugs	48 (96)

Table 3: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

Additional file 1: Availability of services, equipment, supplies, protocols and registers /forms by health facility level.

Indicator (N= Total number of items)	Health facilities			
	All N=20	Hospital and Level IV N=2	Level III N=6	Level II N=12
Services availability (12)				
Skilled person to deliver present 24/7	15	2	6	7
Conduct normal deliveries	16	2	6	8
Newborn resuscitation	11	2	6	3
Kangaroo mother care (KMC)	6	2	4	0
Parenteral administration of antibiotics	17	2	5	10
Parenteral administration of oxytocic	11	2	5	4
Parenteral administration of anti convulsant	9	1	4	4
Assisted vaginal delivery	2	0	2	0
Manual removal of placenta	11	2	5	4
Manual removal of retained products	13	2	6	5
Provide corticosteroids for preterm labor	3	1	2	0
Service score for KMC and Resuscitation	*42.5%*	*100%*	*83.3%*	*12.5%*
Service availability mean score	*47.5%*	*75%*	*70.8%*	*31.3%*
Newborn equipment and supplies (7)				
Steriliser	15	2	5	8
Resuscitation table	6	1	4	1
Infant scale	13	2	6	5
Thermometer	13	1	5	7
Newborn mask	11	2	6	3
Nasal Gastric -tube for newborn	1	0	1	0
Canula for newborn	8	2	4	2
Newborn equipment and supplies mean availability score	*47.9%*	*71.4%*	*73.8%*	*30.9%*
Supplies in delivery room (3)				
Disinfectant	4	0	2	2
Sharps disposal box	18	2	6	10
Soap and hand washing	18	2	6	10
Supplies in delivery room mean availability score	*66.7%*	*66.7%*	*77.8%*	*61.1%*

Additional file 1continued

Indicator (N= Total number of items)	Health facilities			
	All N=20	Hospital and Level IV N=2	Level III N=6	Level II N=12
Space for newborn services (2)				
Separate postnatal area from delivery room	14	2	6	6
Room for KMC or Integrated area for KMC	6	2	4	0
Space for newborn services mean availability score	*50.0%*	*100.0%*	*83.3%*	*25.0%*
Equipment /supplies in postnatal area (8)				
Newborn mask	3	0	2	1
Infant scale	3	0	2	1
Thermometer	4	0	2	2
Steriliser	4	0	2	2
Newborn Nasal Gastric tube	1	0	1	0
Newborn canula	2	0	1	1
Disinfectant	4	0	2	2
Sharp disposal	4	0	2	2
Equipment /supplies in postnatal area mean availability score	*15.6%*	*0%*	*29.2%*	*11.5%*
Maternal and newborn drugs (13)				
Oxytocin	8	2	6	2
Magnesium sulphate	6	2	4	0
Corticosteroid	5	1	4	0
Multivitamin syrup	2	0	1	1
Vitamin K	1	1	0	0
Intravenous drugs	12	2	6	4
50% Dextrose	8	2	5	1
Tetracycline ointment	16	2	6	8
Adrenaline	1	0	1	0
Phenorbabitone	6	2	4	0
PMTCT drug	10	2	6	2
Gentamycin	9	2	5	2
Ampicillin	4	1	3	0
Mean availability score for injectable (gentamycin and ampicillin)	*32.5%*	*75.0%*	*67.0%*	*8.0%*
Mean availability score for all drugs	*33.8%*	*92.3%*	*65.4%*	*12.8%*

Additional file 1 continued

Indicator (N= Total number of items)	Health facilities			
	All N=20	Hospital and Level IV N=2	Level III N=6	Level II N=12
Protocols and guidelines (6)				
Emergency obstetric care (MOH)	1	0	1	0
Newborn Resuscitation (MOH)	7	1	3	3
Essential newborn care (MOH)	6	1	2	3
Newborn standards (MOH)	4	0	2	2
*IMPAC (WHO)	3	0	0	3
Management of preterm (MOH)	3	1	0	2
Protocol and guideline mean availability score	*20.0%*	*25.0%*	*19.0%*	*18.0%*
Register s and forms (8)				
Antenatal registers	18	2	6	10
Postnatal registers	15	1	6	8
Birth registers	15	1	6	8
Partographs	10	2	4	4
Immunisation cards	16	2	5	9
Discharge forms	2	0	2	0
Referral forms	6	1	2	3
Death certificates	2	1	1	0
Register and forms mean availability score	*52.5%*	*62.5%*	*62.5*	*43.8%*

*IMPAC =Intergrated Management of Pregnancy and Childbirth

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