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**Understanding Newborn Care in Uganda  
– Towards Future Interventions**

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The front cover pictures: the first shows a male community health worker making a home visit in the first week after birth. and the second picture shows two health newborn babies delivered under a skilled provider in a hospital setting. The picture at the back shows a couple being transported to a health facility for delivery. Such motorcycles, commonly called *boda boda*, are a common means of transport in peri-urban Uganda. All pictures were taken by the Uganda Newborn Study team

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*To Daddy with honour and love*

**“Knowing is not enough, we must apply; willing is not enough,  
we must do.”**  
**- *Goethe***

## ABSTRACT

**Background:** The highest rates of newborn deaths are in Africa. Existing evidence-based interventions could reduce up to 72% of the 3.8 million newborn deaths which occur every year worldwide, but are yet to be operationalised at scale in sub-Saharan health systems.

**Aim:** To explore community perceptions, determine uptake of evidence-based newborn care practices, and identify delays leading to newborn deaths in Uganda.

**Methods:** Studies were conducted from 2007 to 2009 in Iganga and Mayuge districts in eastern Uganda, and in an embedded Health Demographic Surveillance Site (HDSS) as follows: Qualitative methods with focus group discussions and in-depth interviews (I and IV); a population based cross-sectional study (II) and a case series approach of newborn deaths in the HDSS (III); and a health facility survey (III and IV). A wealth index was generated using principal component analysis of household assets, and was used as a proxy for socio-economic status (II and III). Verbal and social autopsy and a modified maternal mortality delay model were used to code causes and care-seeking delays of newborn deaths (III). Standard descriptive analysis (III) and content analysis were done (I and IV). Newborn care practices were coded as binary composite outcomes (optimal thermal care, good cord care, and good neonatal feeding) and multiple logistic regression analysis was done (II).

**Results:** Most of the evidence-based newborn care practices were acceptable to community members but not promoted by health providers (I and IV). There was poor uptake of newborn care practices among both the poorest and least poor (II). Some practices like putting nothing on the umbilical cord and delaying bathing were less acceptable to caregivers (I). Only 42%, 38%, and 57% of newborns were judged to have had optimal thermal care, good cord care, and good neonatal feeding, respectively (II). Some mothers were putting powder on the cord; using a bottle to feed the baby and mixing/replacing breast milk with various substitutes (I, II and IV). Multiparous mothers were less likely to have safe cord practices (OR 0.5, CI 0.3 – 0.9), and so were mothers whose labour began at night (OR 0.6, CI 0.4 – 0.9) (II). 33% of 64 newborn babies had died in a hospital/health centre, 13% in private clinics and 54% died elsewhere (III). The median time to seeking care was 3 days from illness onset (IQR 1-6) (III). Major delays related to deaths of newborn babies were Delay 1 (delay in problem recognition and deciding to seek outside care) (50%) and Delay 3 (delay in receiving treatment at a health facility) (30%) (III). Health facilities lacked equipment, drugs, supplies and protocols for newborn care, and health workers had correct knowledge on only 31% of the survey questions related to newborn care (III). Care practices for preterm babies at home and at health facilities were of poor quality and potentially harmful (IV).

**Discussion:** Implementation of evidence-based newborn care practices needs to be tailored to the local context. In order to reduce newborn deaths, a universal strategy targeting the entire population is needed and should utilise the many missed opportunities in current programmes. Capacity to manage newborns should be built at health facilities, including private clinics and those at the lower level. Community health workers in health facility-linked preventive and curative newborn programmes may assist in underserved areas.

**Key words:** Evidence-based, newborn care practices, preterm care, community health workers, delays, continuum of care, Uganda

#### LIST OF PUBLICATIONS

- I. **Waiswa, P.**, Kemigisa, M., Kiguli, J., Naikoba, S., Pariyo, G. W., Peterson, S. Acceptability of evidence-based neonatal care practices in rural Uganda - implications for programming, *BMC Pregnancy & Childbirth*, 8 (21) (2008).
- II. **Waiswa P.**, Peterson S, Tomson G, Pariyo G. W., (2009). Poor newborn care practices – a population based study in eastern Uganda, *BMC Pregnancy and Childbirth* 2010, 10:9
- III. **Waiswa P.**, Karin Kallander, Peterson S, Tomson G, Pariyo G. W., (2009). Using the three delays model to understand why newborn babies die in Eastern Uganda (Submitted)
- IV. **Waiswa P.**, Nyanzi S, Namusoko SK., Peterson S., Tomson G, Pariyo G. W., (2009). *“I never thought that this baby would survive; I thought that it would die any time”*: Perceptions and care for preterm babies in eastern Uganda (Submitted)

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

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## LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti Retroviral Therapy
CHW	Community Health Worker
CMR	Child Mortality Rate
FGD	Focus Group Discussion
HBMF	Home Based Management of Fever
HDSS	Health and demographic surveillance site
HC	Health centre
HIV	Human Immune Deficiency Virus
HSD	Health Sub District
HSSP	Health Sector Strategic Plan
ICD	International Classification of Diseases
IDI	In-depth Interview
IMCI	Integrated Management of Childhood Illnesses
IPT	Intermittent presumptive treatment
IQR	Inter-quartile range
KI	Key Informant
KMC	Kangaroo mother care
LIC	Low Income Countries
MDG	Millennium Development Goal
MoH	Ministry of Health
NGO	Non Government Organisation
NMR	Neonatal Mortality Rate
PCA	Principal component analysis
PMTCT	Prevention of Mother To Child Transmission of HIV/AIDS
RESCUER	Rural Extended Services and Care of Ultimate Emergency Relief
SA	Social autopsy
SES	Social Economic Status
SP	Sulfadoxine-pyremethamine
SSA	Sub-Saharan Africa
TBA	Traditional Birth Attendant
TRA	Theory of Reasoned Action
UNFPA	United Nations Population Fund
UNICEF	United Nations Children Education Fund
USAID	United States Agency for International Development
VA	Verbal Autopsy
VHT	Village Health Team
WHO	World Health Organization

## **DEFINITIONS**

**Early neonatal death:** Death in the first 7 days of life.

**Stillbirth:** Here taken as late-stage foetal death, that is, a baby born with no signs of life after 28 weeks of gestation (equivalent to 1000 g) (Lawn et al., 2009c)

**Stillbirth rate:** The number of babies born dead after 28 weeks of gestation per 1,000 total births.

**Early neonatal mortality rate:** The number of early neonatal deaths (i.e. deaths in the first seven days of life) per 1,000 live births.

**Perinatal period:** This time interval includes some portion of late pregnancy and some or all of the first month of life.

**Neonatal period:** Commences at birth and ends 28 completed days after birth

**Neonatal deaths:** This is the death of a newborn during the first 28 completed days after birth. Early neonatal death occurs within the first seven days of life, and late neonatal death occurring after the seventh day but before the 28 completed days of life.

**Evidence-based:** Is a term used to describe the application of empirically acquired knowledge in practice (Mason, 2005, McKibbin, 1998)

**Implementation research:** Is the scientific study of methods to promote use of research findings. It explores the challenges that are faced when generalising research findings ‘in the real world’ (Walker et al., 2003).

## **PREFACE**

Born in a large family but in a poor community, I grew up knowing death, including some very painful experiences involving my siblings, and most were so sudden and I have never understood why they died. It is also painful to investigate deaths, especially of people close to you. So, despite the losses I have experienced and the expertise I have developed, there still remains some I wish to avoid. And yet, every death pains, especially to those directly affected. However, a death, especially of the youngest (neonates and stillbirths) in my village, disappears so quickly in people's minds, and even the physical signs of the grave don't last.

My road to these heights in education has been quite a bumpy one but this is a story for another day. But despite challenges, some people are born lucky, and so I have been. Starting in dusty classes and sometimes studying under trees in the heat of tropical Uganda, where we even never had drinking water all day at school, I somehow made it. And as much as I know, became the only person from my primary class to go on to get a degree. Although my childhood dream was to become an engineer, after consultations with a few people I knew in my village who had a degree, I ended up in Mbarara University Medical School, where I trained to become a doctor. This is also where I learnt my initial research skills.

After completing internship in 1999, I got a good job in the capital, Kampala, with one of Uganda's largest non-governmental organisations. However, in 2000 I moved on to a government job in rural Uganda based in my home town, Iganga, and worked in the same place until 2008. Here, working as a young medical doctor in the villages, I was once again faced by the community's ill health, disease, and poverty. Key questions lingered in my mind: Why these many stillbirths? Why so many neonatal tetanus deaths? Why so many home births and deaths? And, why was there such high fertility in the community? A major recollection I have was that of a feeling of powerlessness among community members that nothing could be done about their situation. My search for answers almost made me an activist – mobilising communities, talking to people, joining NGOs as a volunteer, and writing in news papers and semi-scientific articles in the Uganda Health Bulletin. Little did I know that through enthusiasm I opened my own doors! It was in this search for answers that my future supervisors found me.

After my Master of Public Health degree at the Hebrew University, Jerusalem, Israel, I went back to my district job in my small home town Iganga in 2004, but also helped Makerere University establish the Iganga/Mayuge Health and Demographic Surveillance Site in Uganda, where I later went on to conduct my studies. In 2006, I was offered a PhD position, and I chose my long time preoccupation, neonatal health and why children die, as an area of research. My aim was to sort of perform "*a healthcare delivery system audit*" of newborn care, emphasizing both home and facility care, and the linkages there-in at implementation level. It is my hope that this work helps to contribute towards understanding why so many newborn babies die, thereby inform the design and delivery of health systems-wide interventions in Uganda and beyond.

## 1 INTRODUCTION

Each year, a staggering 7 million children die, either during the first four weeks of life (3.8 million) or as stillbirth (3.2 million). Ninety-eight percent of these deaths occur in low income countries (LICs) (Lawn et al., 2009c, Lawn et al., 2008, Lawn et al., 2009b). In recent decades, child survival has witnessed significant strides in reducing under-five child mortality; however, reductions in newborn mortality remain dismal, particularly in the first week of life (Lawn et al., 2009b).

Despite the incomprehensible magnitude of avoidable premature deaths, neonatal health has historically been a forgotten area, left between the cracks of safe motherhood and child health programmes (Bhutta, 2004, Bhutta et al., 2008a, Lawn et al., 2005b, Lawn et al., 2009b). Unfortunately, this relative neglect is at all levels: neonatal health has been absent from international policy, national programmes and at the implementation level (Lawn et al., 2005b, Lawn et al., 2009b). Further, the Safe Motherhood Initiative, launched over twenty years ago, focused mainly on reducing maternal mortality (Starrs, 2006). Until only recently, childhood initiatives such as the integrated management of childhood illnesses (IMCI) did not benefit or include the newborn (Darmstadt et al., 2005, Jones et al., 2003, Lawn et al., 2005b). Such neglect of interventions has been most significant in sub-Saharan Africa (SSA), where mortality rates are highest (Lawn et al., 2009b, Lawn et al., 2005b).

The health and interests of the mother and child cannot be separated (Knippenberg et al., 2005), and most of the newborn interventions also benefit the mother (Darmstadt et al., 2005). Thus, when the magnitude of mortality and its associated ethical and human rights issues (Tinker et al., 2005) are considered (especially in this era of globalisation), it has become surprising over time that newborn interventions have not been targeted in programmes aimed at attending the health of the mother. Some of the reasons for this might lay in myths, where it is believed that neonatal survival cannot be improved without expensive intensive care units (Martines et al., 2005). Yet, by introducing simple but universal interventions such as free antenatal care (ANC), improving care during delivery as well as the availability of antibiotics, improvements demonstrated in western countries have shown a reduction in neonatal mortality from 30 in 1940 to 10 in 1945 (Martines et al., 2005).

Following recent evidence (Darmstadt et al., 2005), many SSA countries are now beginning to introduce neonatal interventions into their national programmes. However, the evidence base required to inform policy and programmes is still too weak due to a paucity of data on neonatal health in SSA (Lawn et al., 2005b). Indeed, most of the currently available data are based on statistical estimates with wide margins of error (Lawn, 2008, Lawn et al., 2005a, Lawn et al., 2004a, Stanton et al., 2006). Many gaps of knowledge on the health situation for neonates in SSA therefore exist, which offers a basis for this thesis.

This work has explored the barriers as well as the facilitators for implementation of the globally recommended evidence-based newborn care interventions in two rural districts of Uganda. Historically, major gains have been made in Uganda for the health of older children, where under-five deaths per 1000 live births dropped from 175 in 1990 to 130 in 2007, and infant mortality per 1000 live births dropped from 106 to 82 over the same period (Unicef, 2008). However, the neonatal mortality rate (NMR) fell only from 31 to 29 per 1000 live births (Uganda Bureau of Statistics (UBOS) and Macro ORC, 2007), offering the single most important barrier to achieving MDG 4. One point of departure thus far established is that various findings presented in this thesis have been used to inform the design of an ongoing community-based facility-linked neonatal intervention (UNEST: Uganda Newborn trial ISRCTN50321130) in the two districts.

## **1.1 BACKGROUND**

### **Newborn Health and the Millennium Development Goals**

The eight Millennium Development Goals (MDGs) which target an end point of 2015 have been said to represent the most widely ratified health and development goals in history. The MDGs directly related to newborn survival are MDG 4 and 5, while other MDGs are less directly related to but are still relevant for newborn health, such as eradicating extreme poverty and hunger, achieving universal primary education, promoting gender equality and empowering women, combat HIV/AIDS, malaria and other diseases, and developing a global partnership for development.

MDG 4 focuses on child survival, aiming for a reduction in under-five child mortality by two-thirds by 2015, with a global target of 32 per 1000 live births (Bryce et al., 2008, Lawn et al., 2005b). However, at current rates, most LICs will not achieve this MDG target (Bryce et al., 2008). It is estimated that the current global NMR is 30 per 1000, meaning that the burden of death in the neonatal period alone approximates the entire MDG 4 target (Lawn et al., 2009b). Currently, only 16 of 68 priority countries are on track to reach the MDG 4 target (Bryce et al., 2008). Available data show that there has been no measurable reduction in early neonatal mortality in LICs over the last decade, and the gap between the rich and the poor continues to widen (Bryce et al., 2008). Hence, reducing neonatal deaths, especially early neonatal mortality, is crucial to meeting the MDG 4 target (Lawn et al., 2009b). However, evidence shows that most of the neonatal deaths are intimately linked to maternal problems (MDG 5), especially those related to the management of the intra-partum period (Lawn et al., 2009b, Harvey et al., 2002, Darmstadt et al., 2005).

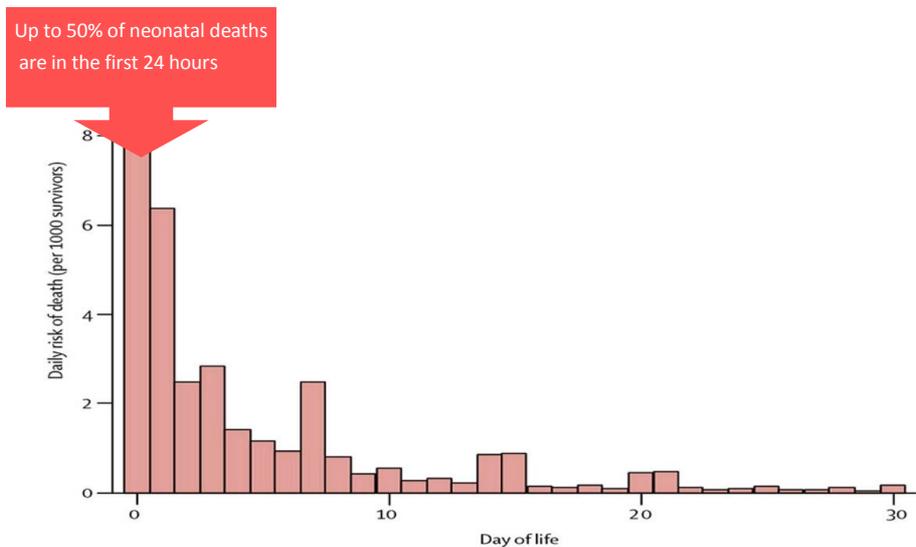
### **Newborn epidemiology**

Ninety-nine percent of newborn deaths occur in low and middle income countries, and the majority of these countries lack vital registration systems (Lawn et al., 2005b). As a result, the current global burden of newborn deaths is based on statistical modelling (Lawn et al., 2005b).

Many deaths among the poorest, and those occurring in difficult to reach rural and urban areas, remain uncouned in official statistics (Lawn et al., 2005b) because they occur at home and are unseen. Thus, there remains a scarcity of data on newborn health in low and middle income countries. Some observers have termed this as the ‘inverse information law’, where “the communities with the most neonatal deaths have the least information on these deaths, and the least access to cost-effective interventions to prevent them” (Lawn et al., 2005b). Follows next is the ‘inverse care law’: “the availability of good medical care tends to vary inversely with the need for it in the population served” (Hart, 1971). It has been documented that in many societies in SSA and South Asia, babies are not named until six weeks of life, and when a baby dies, the mourning of mothers and families is often hidden.

*Neonatal deaths – highest risk is the period during and immediately after birth*

The neonatal period is only 1/60 of the first five years of life, but estimates from 2009 show that neonatal mortality accounts for 42% of under-five deaths, as compared to 37% in 2000 (Lawn et al., 2009b). The proportionate increment is only relative, explained by the fact that while post-neonatal mortality is being reduced, there has also been limited progress in reducing the neonatal mortality rate. Of the estimated 3.8 million neonatal deaths occurring during the first month of life, 3 million die in the first week after birth (Figure 1).



Source: Lawn JE et al Lancet 2005

**Figure 1: Newborn deaths by day of death**

The average daily mortality rate during the neonatal period is close to 30-fold higher than during the post-neonatal period (Lawn et al., 2005b). This is also the period when most maternal deaths occur. Annually, more than half a million women die of pregnancy related conditions (Hill et al., 2007), which means that the period during and immediately after birth represents a critical gap in the continuum of care; and yet, a huge skilled care gap exists, where 47% of all mothers and newborns in developing countries do not receive skilled care during birth (Bryce et al., 2008). There is also a significant quality gap even among those who are delivered by skilled attendants (Hofmeyr et al., 2009), which is a missed opportunity to improve maternal and newborn survival.

In high income countries, the average NMR is 4 per 1000 live births compared to an average 33.1 per 1000 live births in low income countries (Lawn et al., 2004b). Whereas Asian countries have the largest absolute numbers of deaths due to the large populations in the region, countries with the highest rates of neonatal mortality are mostly in sub-Saharan Africa. In addition, globally about two-thirds of newborn babies do not receive any postnatal care, leading to mortality and morbidity from avoidable causes (Bryce et al., 2008).

#### *Stillbirths – 3.2 million per year but are invisible in global policy*

Recent global estimates suggest that at least 3.2 million babies are born dead each year (Stanton et al., 2006). As for neonatal deaths, while the highest absolute numbers of stillbirths occur in South Asia, driven by the large population size of that region, the incidence rates are highest in sub-Saharan Africa (Stanton et al., 2006). In high-income countries, stillbirth rates are below 5 per 1000 births, compared to approximately 32 per 1000 in low and middle income countries (Stanton et al., 2006). In addition, in LICs, the rich in each country experience fewer stillbirths than the poorest, most likely due to inequalities in access to and quality of health care. Here again, despite the huge numbers of stillbirths, these deaths are not usually part of local data collection systems and are also invisible in global policy and programme priorities (Lawn et al., 2009c). As such, the pain of loss of a term pregnancy or a newborn is often felt only by families, and especially by women.

#### **Epidemiology of neonatal mortality in sub-Saharan Africa**

Africa accounts for only 11 percent of the world's population, but it contributes more than 25 percent of the world's newborn deaths, which is a reflection of her very high neonatal mortality rates. It is estimated that of every four children who die in Africa, one is a newborn (Lawn et al., 2005b). The latter is likely to increase due to improvements in survival of older children. Each year in Africa, around 1.16 million babies die in their first month of life (Lawn et al., 2004b), and approximately 1 million babies are stillborn of whom at least 300,000 die during labour (Lawn et al., 2009b).

The risk of dying during the first day of life for a baby in Africa is very high, close to 10 per 1,000 live births, or one percent (Lawn et al., 2005b). Thus, for babies (and their mothers) in SSA, birth and the first day after birth is the time of greatest risk for death.

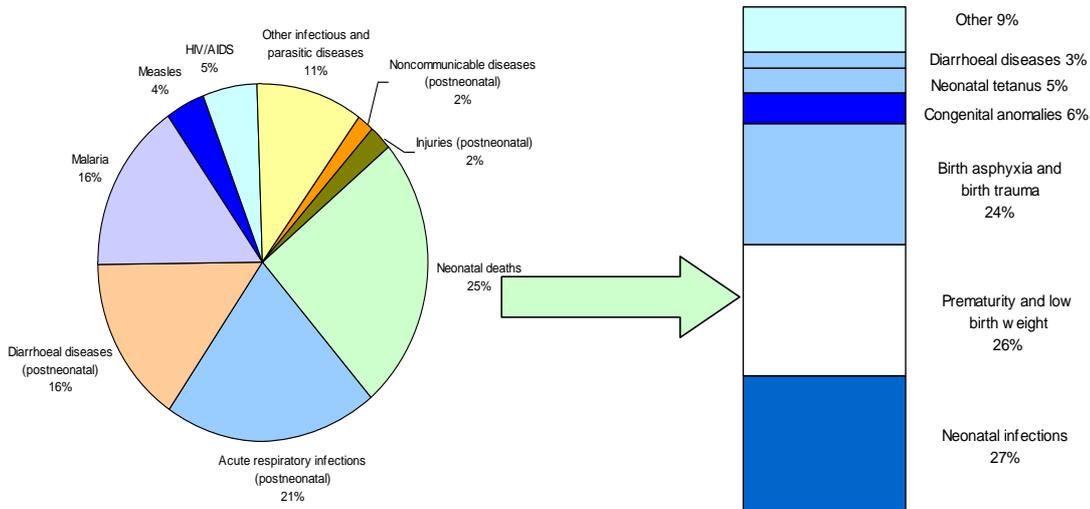
**Ascertaining causes of newborn deaths in low and middle income countries – the role of verbal and social autopsy**

*Causes of newborn deaths*

Of the global 3.8 million newborn deaths, most primarily result from three preventable causes (Figure 2), namely, preterm births (28%), severe infections (36%, including sepsis/pneumonia [26%], tetanus [7%], and diarrhoea [3%]), and complications of birth asphyxia (23%) (Lawn et al., 2004b). In very high-mortality settings, almost 50% of deaths are due to severe infection, tetanus, and diarrhoea; whereas in low mortality settings, preterm-related deaths predominate. At low NMR levels (NMR < 15), sepsis/pneumonia accounts for less than 20% of deaths, and tetanus and diarrhoea are almost non-existent as causes of neonatal death (Lawn et al., 2004b).

**Deaths among children under-five years**

**Neonatal deaths**



Source: WHO. The Global Burden of Disease: 2004 update (2008)

**Figure 2: Causes of newborn deaths**

Neonatal infections are the single most important cause of newborn deaths, particularly sepsis, pneumonia and tetanus. However, infections can be prevented through adequate promotion of antenatal care, hygienic care during childbirth and the postnatal period (including clean cord care), and early and exclusive breastfeeding, and through tetanus toxoid immunisation for neonatal tetanus. In addition, neonatal infections can be treated through current programmes (Lawn et al., 2009a), if access to basic but effective neonatal antibiotics is assured.

Birth asphyxia, recently proposed to be called intrapartum-related neonatal deaths (Lawn et al., 2009b), can be most effectively prevented through skilled attendance and emergence obstetric care (Darmstadt et al., 2005, Adam et al., 2005).

Babies who may be born when they are not severely preterm (33-37 weeks of gestation or 1500g or more) can survive with basic care. Preterm deaths includes only babies who die either because they are severely preterm or result from complications specific to preterm birth, and not those who die of say infections. It is generally thought that most low birth weight babies in Africa are preterm. For moderately preterm babies, critical care entails attention to feeding, warm care, and early treatment of problems including breathing problems, infections and jaundice (Lawn et al., 2009a). In addition, it is recommended that these babies be given kangaroo mother care (KMC), which includes strapping the baby skin-to-skin in the chest, and can be continued at home (Conde-Agudelo et al., 2003).

### **Verbal autopsy**

Ascertaining causes of newborn death has been faced with many limitations in LICs. However, one method, known as verbal autopsy, has been utilised in the effort to collect necessary data from the newborn death event. Verbal autopsy (VA) is a post-mortem in-depth interview with the primary caregiver of the deceased. In many LICs, VA is increasingly becoming a method of choice to generate data on cause of death (Soleman et al., 2006). VA is used because in many LICs, most newborn deaths occur at home, outside the formal health sector, and vital registration systems are lacking. In addition, few newborn deaths are attended by qualified medical professionals who have the ability to attribute a cause of death (Lawn et al., 2005b). Even when a death occurs in a health facility or a hospital, recording of cause of death is not regular or standard, and virtually no diagnostic autopsies are ever conducted. And yet data on causes of deaths are crucial for health sector planning, prioritisation, and for assessing the impact of interventions. Indeed, it has been stated that countries that cannot record the number of people who die or why they die cannot realise the full potential of their health systems (Baiden et al., 2007). However, in practice, this is not always possible.

Open-history narratives or closed-ended questions, or both, is used to conduct VA. These tools include questions about the signs, symptoms and events surrounding the event of death. In the case of child death, the post-mortem interview is usually done with the mother. This method has two underlying assumptions, (1) each cause of death investigated has a set of observable symptoms that can be recognised and

recalled by the primary caregiver, and (2) the characteristics of one cause of death can be distinguished from those of all others (Thatte et al., 2009).

Whereas VA methods for ascertaining cause of deaths for children older than one month and for adults are well developed, those used to evaluate neonates are relatively new. Historically, studies either excluded neonatal deaths or grouped them as 'other' childhood or 'perinatal' causes (Awasthi et al., 1996, Morris et al., 2003, Nykanen et al., 1995, Yassin, 2000). Some of the major reasons given for this were that neonatal cases were considered as relatively few or because neonatal causes of death can be particularly difficult to classify due to nonspecific signs and symptoms in sick newborns (Awasthi et al., 1996, Marsh et al., 2003, Spika et al., 1989, Terra de Souza et al., 2000).

A commonly used hierarchy for coding newborn deaths is that developed by the Child Health Epidemiology Research Group (CHERG) (uses the hierarchy from congenital abnormality through neonatal tetanus, preterm, birth asphyxia sepsis/pneumonia, diarrhoea to other) to estimate the cause distribution of neonatal deaths (Lawn et al., 2006). However, even this has a limitation, as it assumes that each neonatal death is due to a single cause, which is not always true.

## **Social autopsy**

Verbal autopsy can be complemented by social autopsy. Social autopsy (SA) examines the non-medical circumstances surrounding the death in an attempt to understand the underlying causes of mortality. Although most studies estimate only the cause of death among newborns, for health programming it is equally important to understand the care-seeking processes and treatment actions that occurred prior to each death (Bojalil et al., 2007). Both the routine death investigation and the VA do not include questions on care-seeking prior to death, thereby limiting a more complete understanding of the death event. The SA method attempts to elucidate valuable information on any inadequacies or modifiable factors in the home, community, health facilities and the referral mechanisms, which could guide programming and policy. It has thus been suggested that social autopsy is a useful tool that needs further development, validation and use (Barnes-Josiah et al., 1998).

A number of studies using various data collection methods and analyses have been carried out to study care-seeking for fatal illnesses or to conduct social/mortality audit in children (Kallander et al., 2008, Bojalil et al., 2007, Krug et al., 2006, Kalter et al., 2003). However, the employed methods may be unsuitable for newborn deaths because most newborn deaths are related to maternal conditions and care-seeking.

For older children, a commonly used care-seeking model is the “Pathway to Survival” which was developed in recognition that outcomes of childhood illnesses in developing countries depends greatly on the behaviour of the caregiver (Claeson and Waldman, 2000). The pathway focuses on modifiable behaviours of both the child's caregiver and the health care provider, including the management of illnesses at home, care-seeking outside the home, provision of quality health care and compliance with outside treatment (Claeson and Waldman, 2000, Walderman, 1995). However, there has been limited application of the framework for analysis of care-seeking processes for newborn illnesses, which are mainly related to care-seeking during pregnancy and delivery.

In the above section, I have shown the magnitude of newborn deaths in SSA, and the fact that the available information is based on estimates. In addition, I have also shown that despite the huge number of deaths, global and local policies have generally neglected newborn health. In the next sections, I provide an overview of possible interventions. However, as I will show, there has been up to now a lack of successful scalable evidence from SSA, and yet this missing information would be crucial for driving policies and programmes.

## **1.2 EVIDENCE-BASED INTERVENTIONS TO IMPROVE NEWBORN SURVIVAL**

In one of the landmark analyses conducted by the Bellagio Child Survival Study Group in 2003, they hypothesised that under optimal delivery (universal coverage and acceptance), evidence-based child and neonatal health interventions could prevent 63% of under-five child deaths and up to 55% of neonatal deaths (Jones et al., 2003). In 2005, the Lancet Neonatal Survival Series group built upon this concept of organising and packaging neonatal health interventions for effective delivery by three service delivery modes, which included family-community, outreach, or facility-based clinical care (Bhutta, 2005, Darmstadt et al., 2005). Interventions were packaged according to target populations, time period of implementation and service delivery mode (Bhutta, 2005, Knippenberg et al., 2005) as this is recommended in the health systems context (Travis et al., 2004).

The Lancet Series identified 16 interventions which were judged to be of proven efficacy (implementation under ideal conditions) for neonatal survival (Table 1). In this thesis, I investigated 8 of the 16 evidence-based practices as follows: tetanus toxoid immunisation and Intermittent preventive treatment for malaria (IPT) (antenatal period); skilled birth attendance at delivery and clean delivery practices (intra-partum period); resuscitation of the newborn, breastfeeding, and prevention and management of hypothermia and KMC (postnatal period).

All packages of care outlined in the Lancet Neonatal Series were judged to be cost-effective as compared with single interventions. It was estimated that universal (99%) coverage of these interventions could avert an estimated 41 - 72% of neonatal deaths worldwide (Darmstadt et al., 2005). A combination of universal (for all settings) – outreach and family-community care at 90% coverage averts 18–37% of neonatal deaths. The authors concluded that early success in averting neonatal deaths was possible in settings with high mortality and weak health systems through outreach and family-community care, including health education meant to improve home-care practices, to create demand for skilled care and to improve care-seeking (Darmstadt et al., 2005).

Other recent reviews have indicated that perinatal audit could reduce facility-based perinatal deaths by 30% (95% CI 21% – 38%) (Pattinson et al., 2009). A similar proportion could be saved through facility-based basic neonatal resuscitation (Wall et al., 2009).

It has been proposed that to be effective, interventions to improve newborn health should be delivered using the continuum of care approach (Darmstadt et al., 2005, Kerber et al., 2007). The continuum of maternal, newborn and child care can be defined over the dimension of time/throughout the lifecycle (care from before, during and after pregnancy or postnatal/postpartum care) and over the dimension of place or level of care (household through primary to tertiary health facilities). The continuum of care is

now considered a core principle for programmes seeking to improve maternal, newborn and child health. The continuum of maternal and newborn care was developed as a response to the interrelated health needs of mothers and newborns, and hence, the need to integrate interventions. The continuum is advocated for as a model of primary health care that embraces every stage of maternal, newborn and child health. It has been proposed that the success of this framework, however, depends on delivering essential services and implementing improved practices at key points in the life cycle, linking mothers, newborns and their households and communities with quality basic health care and maternity services.

**Table 1: Evidence-based interventions at different periods of the maternal and newborn continuum of care**

Life cycle period	Intervention
Pre-conceptual period	<ul style="list-style-type: none"> <li>• Folic acid supplementation</li> </ul>
Antenatal period	<ul style="list-style-type: none"> <li>• Tetanus toxoid immunisation*</li> <li>• Syphilis screening and treatment</li> <li>• Prevention of pre-eclampsia and eclampsia with calcium supplementation</li> <li>• Intermittent preventive treatment for malaria*</li> <li>• Detection, treatment of asymptomatic bacteriuria</li> </ul>
Intra-partum period	<ul style="list-style-type: none"> <li>• Antibiotics for pre-labour preterm rupture of membranes</li> <li>• Corticosteroids for preterm labour</li> <li>• Detection and management of breech delivery</li> <li>• Labour surveillance (with partograph) for early diagnosis of complications</li> <li>• Clean delivery practices*</li> </ul>
Postnatal period	<ul style="list-style-type: none"> <li>• Resuscitation of the newborn*</li> <li>• Breast feeding*</li> <li>• Prevention and management of hypothermia*</li> <li>• Kangaroo Mother Care*</li> <li>• Community-based pneumonia case management</li> </ul>

\* Denotes evidence based newborn practices investigated in this thesis.

### **1.3 THE ROLE OF COMMUNITY HEALTH WORKER PROGRAMMES IN IMPROVING NEONATAL HEALTH IN WEAK HEALTH SYSTEMS**

The lack of human resources available for health represents a global crisis (Chen et al., 2004), and is a major barrier to achieving the health-related MDG targets (Hongoro and McPake, 2004). It is estimated that in SSA, the number of skilled birth attendants is rising by only 2%, and at this rate, only half of deliveries will be attended to by 2015 (Lawn et al., 2009b). This means that the vast majority of non-institutional newborn births will remain at high risk. Given the gravity of this situation, as well as the magnitude of neonatal deaths in the region, task shifting through the use of community health workers (CHWs) for maternal and newborn health may be a plausible strategy. However, this solution is fraught with funding and management constraints. As put by Haines et al and Bhutta et al, community health workers are not a panacea for weak health systems, and will need focussed tasks, adequate remuneration, training, supervision, as well as the active involvement of the communities (Haines et al., 2007a, Bhutta et al., 2008a).

Based on experiences from Asia, there is now accumulating evidence of the potential for CHW programmes to reduce newborn deaths, even in weak health systems (Bhutta et al., 2005, Haines et al., 2007b). However, to date we lack adequate successful experiences from sustained and nationwide CHW programmes.

As has been described above, based on estimates from the Lancet Neonatal Series, outreach and family-community care at 90% coverage could avert a substantial number of neonatal deaths (Darmstadt et al., 2005), suggesting a potential application for programmes aimed at saving newborn lives in weak health systems such as those in SSA. In fact, just recently, WHO and UNICEF, through a joint statement, endorsed a home visit approach in order to improve newborn care in LICs (World Health Organization. Dept. of Child and Adolescent Health and Development. and UNICEF., 2009). The data utilised to support this endorsement, however, come from trials published on newborn CHW interventions in Asia and South America. To date, little or no such reports come from SSA, where neonatal mortality rates are highest. Key questions therefore remain. How generalisable are Asian models to the SSA context? How would CHW programmes for maternal and newborn health work to scale and in a cost-effective manner within a community-facility linked strategy in SSA? Evidence from SSA settings is urgently needed as appropriate for the SSA health systems, policy and cultural context.

Available evidence suggests that to be effective, community mobilisation requires high levels of community involvement (Gummi et al., 1997). CHW programmes for newborns are mediated through mobilisation strategies that may be of different intensity, including approaches that target individuals such as pregnancy and postnatal home visits, as well as peer counselling to promote maternal and newborn care practices (Kumar et al., 2008). Such programmes should also focus on groups with the

aim of behaviour change among individuals (Manandhar et al., 2004, O'Rourke et al., 1998), or should focus on various aspects that are likely to promote action in the wider community so as to minimise barriers to care.

### **Community health worker interventions targeting the individual**

In trial settings conducted throughout Asia, neonatal mortality was reduced through home visits by trained community health workers to promote preventive care and/or to provide curative newborn care (Bang et al., 1999, Bang et al., 2005, Baqui et al., 2008a, Baqui et al., 2009a, Baqui et al., 2009b, Baqui et al., 2008b, Darmstadt et al., 2006, Mannan et al., 2008, Mullany et al., 2008a, World Health Organization. Dept. of Child and Adolescent Health and Development. and UNICEF., 2009).

Through an intense CHW training programme, which included supervision and home visits, Bang and colleagues trained CHWs in rural Maharashtra, India, to resuscitate asphyxiated infants, to manage low birth weight babies, and to treat with injectable antibiotics or with oral antibiotics to those with suspected sepsis (Bang et al., 1999). They reported a 60–70% reduction in neonatal mortality.

In another study, Vishwajeet Kumar and colleagues (Kumar et al., 2008) reported that a package of community-based mobilisation and education targeted at improved newborn care in rural India led to a 52-54% reduction in neonatal mortality and also improved neonatal care practices.

Recently, Baqui and colleagues (Baqui et al., 2008a, Baqui et al., 2009a) documented a 34% reduction in neonatal mortality after 24 months of implementing a package of preventive and curative care through trained CHWs in rural Bangladesh, with referral for illness or domiciliary antibiotic care when referral was not feasible.

### **Group based and community-wide community health worker interventions**

The Warmi Project in rural Bolivia employed the “Community Action Cycle” approach with women's organisations and community members in 50 rural communities to maternal and newborn health (O'Rourke et al., 1998). PMR was reduced from a baseline level of 117 per 1000 to 44 per 1000 from 1990 to 1993 (RR 0.37; 95% CI, 0.25–0.56), due primarily to a reduction in deaths on the first day of life.

The MIRA (Mother and Infant Research Activities) Project, a cluster randomised controlled trial in mountainous Makwanpur district, Nepal, adapted the Warmi approach to link women with primary maternal-neonatal services (Manandhar et al., 2004) with 12 groups of villages. There was a 30% reduction in neonatal mortality (OR 0.70; 95% CI, 0.53–0.94), and a 78% reduction in maternal mortality (OR 0.22; 95% CI, 0.05–0.90) in the intervention clusters compared with the control clusters.

In a pilot project in Hala and Matiari subdistricts of rural Sindh province of Pakistan, Lady Health Workers from within the government health system along with

community volunteers formed village health committees to lead 3-monthly group educational sessions to increase demand for skilled birth care (Bhutta et al., 2008c). Most villages (86%) in intervention clusters established community health committees, of which 31% established emergency funds for transport and hospital fees. In the intervention clusters there was an increase in the proportion of births taking place in public sector facilities (from 18% to 30%), a reduction in home-births (from 79% to 65%), and reductions in stillbirth (65.9 to 43.1 per 1000) and neonatal mortality (57.3 to 41.3 per 1000) rates following the intervention in the absence of major changes in the concurrent control areas.

A number of newborn intervention studies are now taking place in several SSA countries, and are expected to provide more context specific evidence, which will help to further inform newborn policy and programming in Africa.

#### **1.4 STRENGTHENING HEALTH SYSTEMS FOR IMPROVED MATERNAL AND NEWBORN CARE**

Although there is evidence that there are interventions tested elsewhere which may have, with the potential to significantly reduce the current high neonatal mortality in SSA (Darmstadt et al., 2005), implementation of effective interventions is low (Haws et al., 2007) within a health system context. WHO defines a health system as including “all activities whose primary purpose is to promote, restore or maintain health”. The WHO health system framework describes health systems in terms of six core building blocks (World Health Organization., 2007):

- I. Service delivery
- II. Health workforce
- III. Information
- IV. Medical products, vaccines and technologies
- V. Financing and leadership
- VI. Governance (stewardship)

Recently, “Systems Thinking” (ST) has been proposed as a way to strengthen health systems, by taking advantage of the health system building blocks as outlined in the WHO Health Systems framework. ST was proposed after realising that whilst the WHO health system framework describes the components of the system, it does not capture how they articulate and perform in particular settings to produce the required outcomes. “Systems Thinking” is defined as an approach to problem solving that views “problems” as part of a wider dynamic system. It involves a deeper understanding of the linkages, relationships, interactions and behaviours among the elements that characterise the entire system (Savigny et al., 2009), and places people at the centre of the WHO building blocks for the health system.

Other approaches that could be used, either singly or in combination, to strengthen health systems include the capacity building approach proposed by Potter and Brough (Potter and Brough, 2004), the approach known as ‘averting maternal deaths and

disability' (ADDM) Building blocks for emergent obstetric care (Freedman et al., 2007), and the perinatal audit (Pattinson et al., 2009). Potter and Brough (2004) developed a hierarchy of capacity needs which relate broadly to the different 'levels' within the system (individual, organisational, enabling environment), but also to the interactions between them (Potter and Brough, 2004). They identified the broad areas of capacity need as tools, skills, staff and infrastructure, as well as structures, systems and roles.

## **1.5 GENDER AND NEWBORN HEALTH**

Outcome of neonatal care and survival is tied to a strong gender perspective. In the neonatal period, girls have a survival advantage over boys (Ulizzi and Zonta, 2002). On the other hand, especially documented in Asia, care-seeking for girls compared to boys is less (Victora et al., 2003, Nielsen et al., 1997). Further, care for newborn is generally considered as a woman's issue in LICs. In Ghana, it is documented that it is older women and grandmothers who usually determine whether a child needs treatment, and the second most important decision maker is the woman's husband (Bazzano et al., 2008). However, just as for other newborn issues, a paucity of data exist on the influence of gender in newborn health, and this area needs further investigation.

In the section above, I have discussed health systems and newborn health, especially in low income countries, as well as certain challenges to the success of these systems. I have also presented some available opportunities to improve care in this setting. In the next section, I discuss the local context of the Ugandan health system in terms of history, policy and organisation, as well as programmes having specific reference to maternal and newborn care. The section ends by introducing the conceptual framework for the thesis, the rationale and the objectives of the studies.

## **1.6 UGANDA – SETTING THE CONTEXT**

### **The country and the people**

Uganda is a land locked country located in East Africa, and lies to the north along the Equator. Its neighbouring countries are Kenya to the east, the Democratic Republic of Congo and Rwanda to the west, Sudan in the North, and Tanzania to the south. Uganda has a projected population of 32.4 million people (CIA Factbook, 2010). Landmass is about 241,038 km<sup>2</sup> in size and the country has a population density of about 137/ km<sup>2</sup>. Eighteen percent of the country is occupied by open water and swamps, and 12% by forest reserves, game parks and mountains.

An estimated 86% of the population lives in rural areas, and is mainly managed by the small scale peasant mode of production. The country's estimated GDP per capita is US\$1300 and 35% of the population is below the poverty line (lives on less than a dollar a day). Per capita expenditure on health is only US\$12 dollars, and more than half of this is out of pocket expenditure. The country has a very high birth rate of 47.8 per 1000 population, leading to a very young and dependant population, with 50% being 14 years and below, and life expectancy is 51.6 years for men and 53.8 years for women. Uganda is among the poorest countries in the world with 84.9% of the population living on less than a dollar a day.

### **The Ugandan Health System**

Like many newly independent countries in Africa, Uganda had a functioning health care system in the early 1960s. The 1970s and 1980s saw the collapse of government services as the country underwent political upheaval. Health indicators fell dramatically during this period until recently. Since the year 2000, the delivery of health services in Uganda has been decentralised to district level (Table 2). Each higher level supervises the lower level units.

The Ministry of Health plays a stewardship role, providing leadership, standards, funding and policies. On the other hand, districts are responsible for implementation and service delivery. Lower down from the district level are health sub-districts (HSD), which often include about 10-20 lower level health facilities. The HSD is headquartered at a health centre level IV (HC-IV), and is structurally a mini-hospital with an obstetric theatre, wards, laboratories, 1-2 doctors, and several nurses and midwives. However, HC-IVs in the country are operating below standards, with most obstetric theatres being non-functional due to a lack of equipment, personnel or other inputs, or just as a result of neglect. Each HSD has 3-4 HCs level III (HC-III), and this the lowest level at which laboratory services, deliveries and management of newborn babies is allowable by national policy.

HCs level II (HC-II) are more accessible to the population, but they are small, outpatient-only units which cannot admit, deliver, perform laboratory investigations, or

even treat sick newborn babies. They are also often manned by unqualified nurse aides. At the lowest level is HC I, which lacks any physical infrastructure. A HC I is basically a collection of community volunteers, together termed the Village Health Team (VHT). They are responsible for community mobilisation and linking with the formal health facilities. Currently, there are plans for VHTs to start providing community case management of pneumonia in addition to home-based management of fever with pre-packed anti-malarials, a role which they are already playing. However, scale up of VHT structures has been slow and they are not yet formed in the two districts where these studies were done. There are a number of private-not-for profit health units, and these are subsidised by government through primary health care grants. Various local NGOs and community-based organisations (CBOs), focusing primarily on health education, are also active in the sector.

Each health unit in Uganda has a Health Unit Management Committee (HUMC) which is supposed to be the main link between the community and the facility, and consists of both health workers and non-political representatives from the community.

**Table 2: The structure of the Uganda National Health System**

Health Unit Level	Physical structure	Location	Catchment Population
HC-I	None	Village	1,000
HC-II	Outpatient services only	Parish	5,000
HC-III	Outpatient services, Maternity, General Ward and laboratory	Sub-county	20,000
HC-IV	Outpatients, Wards, Theatre, Laboratory and blood transfusion	County	100,000
General hospital	Hospital, laboratory and X- ray	District	100,000–1,000,000
Regional hospital	Specialists services	Region (3–5 districts)	1,000,000–2,000,000
National Referral hospital	Advanced Tertiary Care	National	Over 20,000,000

Note: HC = Health centre; Adapted from Government of Uganda, Health Sector Strategic Plan, 2000/01-2005/05

### **The current situation of maternal and newborn care in Uganda**

Maternal and newborn outcomes remain very poor in Uganda. Table 3 shows selected health indicators from Uganda. The total fertility rate is high at 6.7 per woman, while the mortality rate for under-fives is 137 per 1000 live births, the NMR is 29 per 1000 live births, and the maternal mortality rate is 435 per 100,000 live births (Uganda Bureau of Statistic (UBOS) and Macro ORC, 2007). Antenatal attendance is recommended 4 times, but the attendance rate is only 42%, and supervised deliveries are at 42% of all deliveries (Uganda Bureau of Statistic (UBOS) and Macro ORC,

2007). Antenatal attendance at least once during pregnancy is at 92% and 72% of the population is within 5 km distance of a health facility (Government of Uganda, 2005). Emergency obstetric care met need is only 14% (Orinda et al., 2005, Mbonye et al., 2007), and 12% of newborn babies have low birth weight. Although recommended in policy, in practice virtually no postnatal care exists. In total, an estimated 44,500 neonatal deaths and 45,100 stillbirths occur per year, of which 31,800 could be saved by simple interventions proven to work (Lawn J, 2006). Preventable causes of newborn deaths dominate, with infections and tetanus accounting for an estimated 31% of causes of neonatal deaths, followed by birth asphyxia (27%) and complications of preterm delivery (25%).

**Table 3: Selected Health Indicators over the years 1991 – 2006**

Indicator	1991	1995	2001	2006
Neonatal mortality rate (NMR)			32	29
Infant mortality rate (IMR) per 1000	122	81	88	76
Under five mortality rate per 1000	203	147	152	137
Maternal mortality ratio (MMR) per 100,000	527	506	505	435
Total fertility rate (TFR)			6.9	6.7
Unmet need for family planning			35	40.6
Crude birth rate			52	44.9
Skilled birth attendance			38	42

**Source:** Population secretariat, 2007

HIV/AIDS and malaria are important indirect causes of maternal and newborn deaths in Uganda. Intermittent presumptive treatment (IPT) in pregnancy prevents development of malaria and eliminates malaria parasites from the placenta. During pregnancy, the malaria control guidelines in Uganda recommend the use of at least two doses of SP/Fansidar during the second and third trimester of pregnancy. However, utilisation of IPT remains low. Overall, 37 percent of pregnant women receive at least one dose of SP/Fansidar to prevent malaria during pregnancy, and 18 percent receive two or more doses (Uganda Bureau of Statistic (UBOS) and Macro ORC, 2007). Uganda still remains one of the countries devastated by HIV/AIDS, despite many good reports of success. Reductions in HIV prevalence have levelled off among pregnant women, remaining at 6.5% since 2009; and 20,000 HIV positive infants are born every year to HIV positive mothers, but most die without care. Neonatal mortality is high among the rural population (NMR 33 per 1000 live births) but also among the urban

(NMR 27 per 1000 live births) (Uganda Bureau of Statistic (UBOS) and Macro ORC, 2007).

### **Interventions addressing neonatal mortality**

Uganda has tried several interventions to address its high child, neonatal and maternal mortality. For child survival, key strategies have included roll out of the IMCI to all districts but the current coverage and practice is very low. The Home Based Management of Fever (HBMF) was tried, where pre-packaged anti-malarial drugs are distributed by community volunteers. The HBMF can be seen as a first step toward a Ugandan Community Health Worker programme, and a successful expanded programme for immunisation. However, even for the older child, studies in Uganda have shown glaring gaps for these interventions in regard to both access and quality of care for sick children (Rutebemberwa et al., 2009d, Rutebemberwa et al., 2009c, Rutebemberwa et al., 2009b, Rutebemberwa et al., 2009a, Pariyo et al., 2009, Hildenwall et al., 2009b, Hildenwall et al., 2009a, Bakeera et al., 2009, Kiwanuka et al., 2008, Kallander et al., 2008, Hildenwall et al., 2008, Nsungwa-Sabiiti et al., 2007, Nsabagasani et al., 2007, Hildenwall et al., 2007, Kallander et al., 2006b, Kallander et al., 2006a, Pariyo et al., 2005, Kallander et al., 2005, Nsungwa-Sabiiti et al., 2004).

In addition, the IMCI and HBMF approaches have had major limitations, such as high costs of training and support supervision, limited roll out at community level, lack of guidelines for the newborn, and over focusing on referral advice from health centre to district hospital, which is often unrealistic (Peterson et al., 2004). Moreover, these interventions largely do not include care for the pregnancy and newborn. The country has witnessed tremendous successes in control of immunisable diseases, such as measles, neonatal tetanus and polio, and plans are underway for the elimination of these three conditions. Current interventions which focus on the mother, but also benefit newborn babies, include the promotion of ANC attendance, supervised deliveries, Prevention of Mother to Child Transmission of HIV (PMTCT) and intermittent presumptive treatment (IPT) of malaria.

### **Policy opportunity for scaling up newborn care in Uganda**

Despite the above challenges, there is now a major opportunity to systematically promote newborn health and survival in Uganda. New policies prioritising delivery of integrated maternal-newborn programmes, including use of community strategies, have been developed but are not yet operationalised. These include the new Health Sector Strategic Plan II (HSSP II) (Government of Uganda, 2005), which prioritises newborn care as one of the elements of the Maternal and Child Health clusters. HSSP II has set targets for newborn care (however without indicating baseline values) to reduce low birth weight by 30% and to reduce the proportion of infants seen in the health facilities with septicemia/severe disease by 30%. In addition, the HSSP outlines core essential and emergency newborn care interventions, such as postnatal care for the mother and baby, including monitoring the newborn at least two times during the first week of life. However, delivery mechanisms were not defined for these postnatal contacts in HSSP II and are thus far only being planned as part of a new Health Sector Strategic Plan III, which is currently under development. As a result of the current state of these on-going

developments, a national newborn situation analysis actually showed that little was achieved in terms of coverage of neonatal interventions and indicators (Government of Uganda, 2008).

Furthermore, the country has developed a joint government-development partner plan to address maternal and neonatal mortality in a landmark document entitled “The Roadmap for Accelerating the Reduction of Maternal and Neonatal Mortality and Morbidity in Uganda 2006-2015”. The Roadmap focuses on strengthening coverage of basic interventions within the continuum of care, such as skilled attendance at birth and postnatal care. The challenge also here is to operationalise the Roadmap’s recommendations. Similarly, the VHT strategy has been outlined in the policy as one way of delivering community interventions including identification of a person responsible for reproductive and child health in each village. However, the technical content of what to deliver, to whom and when through the VHT strategy are just being defined. Other opportunities at national level include strategies outlined in documents such as the PMTCT strategy, the Child survival strategy, and the Newborn Implementation Framework.

## **1.7 ACCESS AND EQUITY IN HEALTH CARE**

Access to health services is defined as the timely use of services according to need. However, access has many dimensions. Penchansky and Thomas asserted that access reflects the fit between characteristics and expectations of the providers as well as the clients (Penchansky and Thomas, 1981). They grouped these characteristics into five As of access to care: affordability, availability, accessibility, accommodation, and acceptability.

However, as discussed above, access to neonatal interventions in LICs is not equitable. Inequity in health care has been defined as differences in health that are unnecessary, avoidable, unfair and unjust. On the other hand, equity also means social justice or fairness; it is an ethical concept, grounded in principles of distributive justice. Equity in health is defined as the absence of socially unjust or unfair health disparities. Although the poor often have more morbidity and mortality, they also often access less care. This is an example of the “inverse care law”, that is that “the availability of good medical care tends to vary inversely with need for it in the population served”(Hart, 1971).

Equity of access to health care can also be elucidated from the user or “demand” perspective in contrast to the commonly used provider or “supply” perspective. Access to health care is through different stages, each of which has several potential barriers (Dahlgren and Whitehead, 2007). Demand is determined by perceptions of need.

There are issues to consider in choosing implementation strategies for newborn interventions in order to achieve equity. It has been proposed by Victora and colleagues that two approaches can be considered to improve equity of child health programmes: (1) targeting to the poor, or (2) aiming for universal coverage (Victora et al. 2003). Whereas targeting may allow for ease of reaching the most disadvantaged, it may be difficult to implement as it may be stigmatising or the vulnerable ones may be difficult

to identify, or it may be unethical. Targeting is also not recommended when the majority of the population is at risk the poorest. On the other hand, a universal coverage approach does not require identification of groups to target, but the programme may lose effectiveness because of inadequate coverage in the most disadvantaged groups.

To measure inequities in health care in absence of income data, an asset or “wealth” index, can be derived from questions such as ownership of a number of different assets from a defined list, and has been used as a measure of the long-run, rather than current, economic status by household in many countries (Filmer and Pritchett, 2001). The wealth index is constructed from a set of asset indicators, using principal component analysis to derive the weights. An asset index is produced for each household, on the basis of which households are ranked. Commonly, equity is assessed by dividing the first principal component into quintiles, so that each household is classified as most poor, very poor, poor, less poor, or least poor in terms of socioeconomic status. The wealth index provides a relative rather than absolute indicator of wealth status across households.

## **1.8 HEALTH-SEEKING BEHAVIOUR MODELS**

Health-seeking behaviour models can help to explain how, when, and why people seek care. There are two major approaches which are widely used to explain health care-seeking (Mackian et al., 2004): 1) health-seeking behaviour (which describes the response to illness) and the 2) health care-seeking behaviour (which focuses on the act of seeking health care).

### **The Health Belief Model**

The Health Belief Model (HBM) is possibly the most known health-seeking behaviour model in public health. According to this model, action in the HBM is guided by: Beliefs about the impact of illness and its consequences (*perceived susceptibility and severity*); *Health motivation and consequences beliefs* i.e., perceived benefits and barriers to putting into action health care-seeking; Cues to action which includes different, internal and external factors, which influence action (Janz and Becker, 1984).

### **The Theory of Reasoned Action/Theory of Planned Behaviour**

The Theory of Reasoned Action (TRA) (Fishbein, 1980) assumes that behavioural intention is determined by: Attitudes towards behaviour which is determined by the belief that a specific behaviour will have a concrete consequence (*outcome or value expectancy*); Subjective norms or the belief in whether other relevant persons will approve one’s behaviour (*perceived social norms*), plus the personal motivation to fulfil with the expectations of others (*willingness to comply with those expectations*); Perceived behavioural control or “*external*” context, which is determined by the belief about access to the resources needed in order to act successfully (e.g. personality and demographics). This theory has been used mainly in research on behavioural risks related to HIV/AIDS and in sexually transmitted diseases (Fisher et al., 1995).

Models explaining health care-seeking behaviour include:

### **The Three Delays model**

The three delays model was developed by Thaddeus and Maine (Thaddeus and Maine, 1994) to examine maternal deaths for factors most likely to result from three different delays: (1) delays in recognition of illness and the decision to seek care; (2) delays in arrival at a health facility; and (3) delays in the provision of adequate care once at a health facility. It assesses modifiable delays associated with maternal deaths from the time of onset of obstetric complications to the time of receiving appropriate care. Similar delays have been documented for infants in Uganda and elsewhere. In a Ugandan study, only 21% of severely ill babies referred to higher level facilities completed referral (Peterson et al., 2004). A recent review by Gabrysch and Campbell re-evaluated the three delays model by focusing on the determinants of skilled attendance in low and middle income countries, and identified 20 determinants grouped into four themes: sociocultural factors; perceived benefit/need of skilled attendance; economic accessibility and physical accessibility (Gabrysch and Campbell, 2009).

### **The 'Four As' model:**

The four As model was developed in the 1960s to assist understanding of why families use health care, to define and measure equitable access to health services, and to promote equitable access (Andersen, 1995). The model is summarised as follows: *Affordability* is determined by how the provider's charges relate to the client's ability and willingness to pay for services. *Availability* measures the extent to which the provider has the requisite resources, such as personnel and technology, to meet the needs of the client. *Accessibility* refers to geographic accessibility, which is determined by how easily the client can physically reach the provider's location. *Accommodation* reflects the extent to which the provider's operation is organised in ways that meet the constraints and preferences of the client. And *acceptability* captures the extent to which the client is comfortable with the more immutable characteristics of the provider, and vice versa.

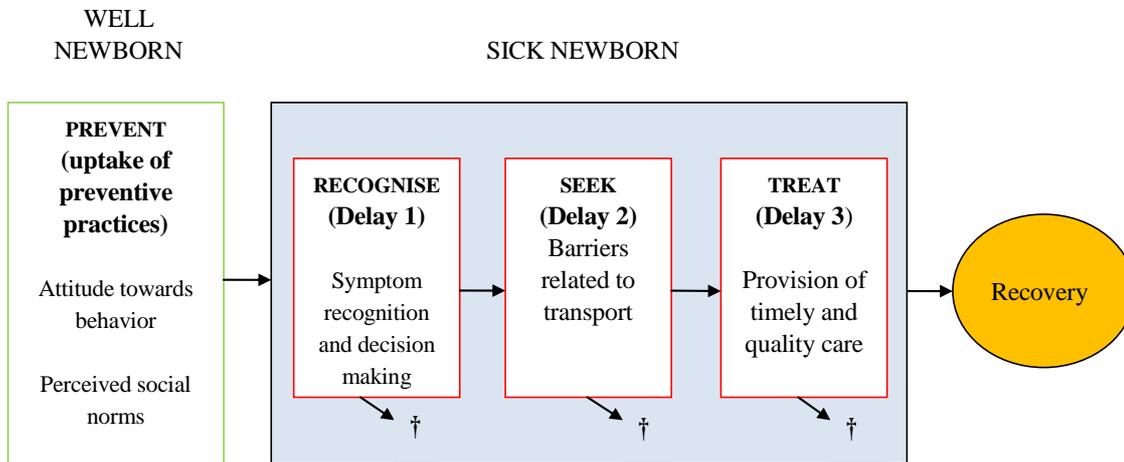
The conceptual framework outlined below borrows from the TRA and the three delay model to evaluate preventive and curative care interventions for newborn babies in the two study districts. The TRA is suitable for explaining what influences the uptake of preventive care practices while the three delays model can be used to describe care-seeking once a newborn falls sick.

## 1.9 CONCEPTUAL FRAMEWORK FOR THIS THESIS

The thesis aims to elucidate reasons for the inadequate newborn preventive care practices and where the delays that lead to the deaths of newborn babies occur. Gaining such understanding is crucial to designing interventions. I thus developed a conceptual framework that combines the theory of reasoned action (TRA) and the three delays model (Thaddeus and Maine, 1994) as modified by UNICEF for the essential steps needed in pneumonia management (Wardlaw et al., 2006). However, because the health of the newborn is closely related to that of its mother, care practices during pregnancy, delivery and immediate newborn care at home and in health facilities are critical in avoiding illness. Finally, once ill, the newborn might die because of delays to care-seeking, and these include: 1) delays in recognition of illness by the caregiver and deciding to seek outside care; 2) delays in reaching a health facility; and 3) delays in receiving quality care while at the health facility. In other words, any gap in uptake of preventive newborn practices and quality of care for sick newborn babies along the entire continuum of maternal and newborn care is critical.

The framework uses the key words “prevent”, “recognise”, “seek” and “treat” to identify different potential barriers to uptake of preventive care practices or to access of care when ill (Figure 3). The framework covers the decision-making process by both health providers and care takers, and includes care-seeking when “well” (care during pregnancy, labour and immediate newborn care, or care for a newborn at home); and when sick or ill: recognition of symptoms and barriers to deciding to seek care outside the home (recognise), to complete care-seeking (seek), and to the provision of quality care (treat). In failing to take up appropriate preventive care practices, in failing to recognise illness and to seek care from outside the home, and in failing to receive adequate treatment, the results can be fatal. The possibility for such progression is illustrated by the arrows between each box. It remains unclear at which step the mortality occurs, or how different steps interact to cause mortality in newborn babies.

In the discussion section of this thesis which will follow the results, the key words “prevent”, “recognise”, “seek” and “treat” will be used, along with other key components of the TRA (such as “positive attitude”) and of the three delays model (such as “delays”). When referring to the model, these key words will be put in italics.



**Figure 3:** Conceptual framework for the thesis, modified after the Theory of Reasoned Action (Fishbein, 1980) and after UNICEF (Wardlaw et al., 2006) and Thadeus and Maine’s Three Delays Model (Thaddeus and Maine, 1994)

### 1.10 RATIONALE FOR THE STUDIES

Despite our awareness about the enormous magnitude that neonatal death has in the global context, as well as the importance these deaths have in our ability to achieve the MDG 4 target within the coming few years to 2015, sub-Saharan Africa has shown no measurable reduction in neonatal deaths for nearly the past decade (Bryce et al., 2008). This comes in spite of the fact that evidence-based knowledge exists of interventions that have the potential to reduce neonatal mortality by 41–72% worldwide (Darmstadt et al., 2005). Most of these interventions have been said to be relatively simple (Adam et al., 2005).

In order to accelerate efforts towards achieving MDG 4, a number of SSA countries including Uganda, are designing initiatives meant to integrate newborn interventions into current maternal and newborn programmes, which is hitherto a neglected area. Most of these efforts are based on global recommendations. Entirely lacking in these recommendations is evidence directly stemming from the SSA context, as most of the current evidence is based on mainly studies from Asia. In fact, WHO and UNICEF have already recommended community based interventions through home visits as one of the key strategies (World Health Organization. Dept. of Child and Adolescent Health and Development. and UNICEF., 2009). However, the absence of evidence from SSA presents a challenge, since the health system context – which includes cultures and local and region-specific practices – may be different than those seen in Asia. How relevant are Asian models for SSA, given that we know that there is no magic “one size fits all” programme to address neonatal mortality?

In Uganda, the globally defined evidence-based newborn interventions have to a less extent already been translated into policy in terms of the HSSP II, the Roadmap for Accelerating the Reduction of Maternal and Neonatal Mortality and Morbidity in Uganda 2006-2015, and the Child Survival Strategy (Government of Uganda, 2005). However, like for many policy initiatives, the translation from global policy to local policy was not preceded by local adaptation of these evidence-based newborn interventions. Evidence or policy on paper sometimes does not usually translate into practice, leading to the so called “know-do gap” (Sanders and Haines, 2006). The local context in terms of epidemiology as well as health system design and performance and community demand are key factors that need to be considered (Knippenberg et al., 2005, Travis et al., 2004). This is crucial for identifying and recognising the extent of the “know-do gap” in current programmes. With this thesis, I aim to inform policy making for newborn interventions, especially as regards the implementation level.

To be effective, implementation activities need to be tailored to the local context. Key features of the “know-do gap” as related to neonatal health at the implementation level in SSA health systems include several barriers and facilitators such as: identifying missed opportunities or modifiable delays within the health care delivery system that lead to newborn deaths; understanding whether the evidence-based, globally recommended practices are acceptable in the local context (home care practices, community perceptions and underlying cultural beliefs); and the current uptake of neonatal interventions including the quality of newborn care gaps across the maternal and newborn care continuum.

### 1.11 OBJECTIVES

**Main objective:** To explore community perceptions, determine uptake of evidence-based newborn care practices, and identify delays leading to newborn deaths in the rural districts of Iganga and Mayuge, as a basis for design of newborn interventions in Uganda.

#### **Specific objectives**

1. To explore the community’s knowledge and perceptions on neonatal care practices and care-seeking behaviour, as well as the perceived quality of the different types of care in Iganga and Mayuge districts, Uganda (Study I and IV).
2. To assess uptake of evidence-based newborn care practices in Iganga and Mayuge districts, Uganda (Study II).
3. To assess delays leading to newborn deaths in Iganga and Mayuge districts, Uganda, using a three delays audit approach (Study III)
4. To explore the current care practices at facilities and at home, as well as related perceptions regarding preterm births in Iganga and Mayuge districts, Uganda (Study IV).

In the above section, I have introduced readers to the Ugandan health system, the conceptual framework for the thesis, the rationale and the objectives of the studies. Next I summarise the study methods, starting with the study setting: Iganga and Mayuge districts and the embedded Health Demographic Surveillance Site; and ending with sample size and a summary of data analysis methods.



Uganda. The Lusoga and Luganda languages and their traditional practices and cultures are similar to each other. For example, the major language of the Basoga is Lu-Soga, which is very similar to Luganda, spoken by the Baganda. Basoga includes some Islands in Lake Victoria such as Buvuma and Sigulu. The Basoga tribe are classified as one of the Bantu ethnic groups, and the majority of Basoga are Christians but the Muslim faith is also growing rapidly, both often in combination with traditional African religious practices. Study II, III, and the health facility component of IV, were conducted in the Iganga/Mayuge health and demographic surveillance site (HDSS), whereas study I, and the qualitative component of study IV, were conducted elsewhere outside the surveillance area in the two districts of Iganga and Mayuge.

### **Iganga district**

Iganga district is located about 120 km east of the capital Kampala, and its population is approximately 672,758 (Government of Uganda, 2009). The district is over 90% rural. Results from the 2002 census indicate that the district has an estimated population growth rate of 3.2%. The district has one hospital, 23 HC-IIIs with delivery services, and 52 facilities providing only outpatient care. However, the health infrastructure, staffing and services remain inadequate as was shown in a recent MOH annual report (Government of Uganda, 2009).

The provision of maternal and child health programmes in Iganga district remains a major challenge, due in part to limited resources and because of the culture-related beliefs and practices that are prevalent in the communities. Although 70% of the population lives within a 5 km radius of a health unit in Iganga, only one-third of these health units provide institutional deliveries or has the right to administer injectable antibiotics to neonates. This effectively makes such distances greater as seeking care means going to higher level facilities.

The institutional delivery coverage has remained very low at 42% for 2009 (Government of Uganda, 2009). Most of these delivery-service health units lack basic equipment, physical infrastructure and staffing, and thus provide very limited obstetric services. Moreover, quality of care is poor even for health facility deliveries, resulting in high maternal and perinatal mortality. For instance, at Iganga general hospital, which conducts the majority of deliveries in the area, out of 1527 deliveries which occurred in the hospital from the months of January to April 2009, there were 110 stillbirths (7.2%) of which 65 (59%) were fresh stillbirths. During the same period, there were 14 maternal deaths (Iganga Hospital Health Management Information System, 2009). It is not clear how many of these deaths were attributable to hospital related quality of care or to delays related to referral.

Although neonatal tetanus used to be a major killer of newborn babies in the area (Gitta et al., 2006), recent figures have shown a significant reduction in its annual prevalence from 120 cases in 2005 to 1-3 cases currently (personal communication, District Health

Officer, Iganga). This is mainly attributed to tetanus vaccination campaigns. Despite these advances, health care for neonates remains universally weak.

### **Mayuge district**

Mayuge is located along the northern shores of Lake Victoria shores and includes six islands. In the eastern region of Uganda, 120km from Kampala, Mayuge is bordered by Iganga to the North, Jinja in the West, and Bugiri in the East. It shares the shores of Lake Victoria with Mukono, Bugiri and Jinja districts. Mayuge was carved out of Bunya County in the Iganga district in year 2000, and has adequate coverage by water: 77% of Mayuge is water.

The district has over 406,658 people (Government of Uganda, 2009). The main occupation of the people is small scale agriculture with a main emphasis on food crops, such as millet, potatoes, beans, Simsim and sunflower. Cash crops also exist, such as cotton and coffee. Fruits and vegetables are also grown, such as tomatoes, passion fruits and onions. Fishing on Lake Victoria is a mainstay, and the farmers keep cattle on the surrounding lands. The district has a total of has one private hospital, two HC-IVs, and 35 lower level health units (Government of Uganda, 2009).

### **Maternal and newborn health in Iganga and Mayuge districts**

Health care delivery and management in Iganga and Mayuge districts was the same until 2000, when Mayuge became an independent, decentralised district, carved-out of Iganga district. As such, historically, health care delivery and services in the two districts was and still is similar. In 1989, the Ministry of Health, with support from UNFPA, introduced the Rural Extended Services and Care of Ultimate Emergency Relief (RESCUER) project in Iganga district in order to improve maternal and neonatal health. The RESCUER project consisted of an ambulance and radio call system, and improvement in the formal health services infrastructure. In addition, community health workers who consisted of mainly traditional birth attendants (TBAs) and community based reproductive health workers (CBRHWs) were identified, trained, equipped, and linked to formal service providers. TBAs were also given radio handsets to call formal service providers for the ambulance and technical support in case of an emergency. According to information from the Office of the District Health Department in Iganga, from 1995 - 2003 there was an increase in ANC attendance and institutional deliveries by 25%, and a decrease in maternal deaths by 46% (48 deaths in 1995 and 26 in 2003). These achievements are attributed mainly to the RESCUER Project. However, the system broke down mainly due to high running costs, and was not affordable by the district once project funding ran out.

Since 2005, with support from Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), and the Ministry of Health, the district has been implementing the PMTCT and

antiretroviral therapy (ART) programmes. Presently, the district has 11 PMTCT and 5 ART static sites. HIV/AIDS service availability in the two districts is high (Government of Uganda, 2009). However, a recent study conducted in the area shows that uptake of PMTCT is low despite a policy of “opt out” (Larsson et al., 2009).

The two districts have a large number of trained TBAs, and these conduct many of the deliveries, despite that they are not adequately supervised. Village Health Teams are not yet operational in the two districts.

### **Iganga/Mayuge Health Demographic Surveillance Site**

Iganga/Mayuge HDSS is situated in the Eastern part of Uganda, and it covers an area across the two districts of Iganga and Mayuge. The HDSS covers 155sqkm, comprising 18 parishes and 65 villages. At the time of data collection, the HDSS population was about 68,000 people, staying in roughly 12,000 households. The average household size is five persons per household, and the main occupation is subsistence agriculture.

The HDSS is comprised largely of a rural area with only Iganga town council being peri-urban. The HDSS is currently expanding to new areas along with an increase in the specific demands for more research.

In Iganga/Mayuge HDSS, there is one general hospital, 15 health centres, about two dozen small private clinics and other informal health providers, mostly traditional birth attendants, drug shops and private clinics that are most often found in small trading centres, as well as in Iganga town (Figure 5). All government and NGO facilities have clinical officers and nurses for health care delivery, apart from delivery provided by the hospital, which also has doctors.



## 2.2 MAIN RESEARCH METHODS

This thesis comprises four studies, with a general aim to inform design of a newborn intervention as tailored to the local context. The studies were timed such that one could inform the next. First, through the HDSS system, assessment was done of causes of newborn deaths, and identified where major delays occurred as they contribute to death. The next study then explored the acceptability of the evidence-based newborn practices, and it helped to inform the design of the variables that were included in the subsequent study, which assessed uptake of newborn care practices among babies who survived the neonatal period. Finally, the picture was completed by seeking to understand the care provided to preterm babies at home and in health facilities as an example of the current care for newborn babies in the study area.

**Table 4: Summary of qualitative and quantitative methods used in the thesis**

Study and focus	Methods	Study population and sample size	Analysis	Year of data collection
Acceptability of evidence-based newborn care practices (I)	10 FGDs and 10 KI interviews	Mothers, fathers, grandparents and child minders  Total 98 respondents	Content analysis	End 2006/Jan 2007
Uptake of newborn care practices (II)	Cross-sectional population based study	Mothers of babies 1-4 months n = 414	Multiple Logistic regression analysis; and PCA	2007
Modifiable delays leading to newborn deaths (III)	Case series	Neonatal deaths n = 64	Descriptive statistics	2006-2008
Care of preterm babies (ptm) (IV)	Health facility survey IDIs FGDs	1 hospital and 15 health units 11 CHWs 10 mothers, 6 fathers and 3 grandmothers of preterm babies 3 FGDs	Content analysis	2009

## **Summary of methods**

### **Cross sectional surveys**

In study II, a cross-sectional survey was conducted in households with babies aged 1-4 months. The study was conducted as part of the routine HDSS update rounds. In this method, a representative sample of the study population of interest is interviewed using a structured guide at one point in time (Bowling, 2002). However, for the purposes of this study, all mothers who had a baby 1-4 months were interviewed, i.e., we conducted a population based survey. Cross-sectional surveys provide point estimates or prevalence, but not incidence data. In a cross-sectional survey, the relationship between an explanatory variable and an outcome can be examined in terms of the presence or absence of outcome (Last, 2001). Cross-sectional surveys have the advantage that when they are field studies, they are conducted in natural settings, and random probability sampling is therefore easier to conduct, which increases validity; findings can also be generalised to the wider study population (Bowling, 2002). A major disadvantage of this method is that it cannot measure incidence (Rothman, 2002), and there may be over reporting or under reporting of some conditions (Lilienfeld and Stolley, 1994).

### **Focus Group Discussions**

In study I and IV, focus group discussions (FGDs) were employed as part of the data collection. FGDs are a relevant method when the researcher wants to describe perceptions, interpretations and beliefs, in order to gain understanding of a particular issue from the perspective of the group's participants (Khan and Manderson, 1992). FGDs exploit the interaction between the participants to explore people's views about the topic being investigated in the particular setting, especially helpful when the researcher wishes to explore people's knowledge and experiences (Dahlgren et al., 2004). FGDs are designed to enable participants to relax and talk freely. FGDs have been said to 'give a voice' to marginalised groups as they can express their opinion (Rice and Ezzy, 1999). However, FGDs may have a disadvantage if the researcher's misconceptions drive the group's interaction (Hardon et al., 2001). Although FGDs may generate in-depth information, they may not explore the complex beliefs and practices of individuals due to the short time involvement of the research team (Rice and Ezzy, 1999). In study I, FGDs were used to gather information from the community on acceptability of the globally recommended newborn care practices. In study IV, FGDs were conducted with the mothers, health workers and community members to explore the kind of care that is provided to preterm babies, as well as any associated beliefs, barriers and facilitators.

### **In-depth Interviews**

In-depth interviews including key informant interviews were used in study I and II. Because peoples' responses are less influenced by the presence of their peers, in-depth interviews are used to discover the subjective meanings and interpretations that people give to their experiences (Rice and Ezzy, 1999). In-depth interviews can also be used when the respondents are influential or well informed people, which gives an overall view of the community perceptions and experiences (Marshall and Rossman, 2006). Thus, in-depth interviews can therefore be complimentary to

FGDs and extend time in order to delve more deeply into respondent experiences. All interviews in study I and II were tape recorded, which enabled more eye contact during the meeting between the moderator and the respondent (Holstein and Gubrium, 1995).

### **Case series approach**

Study III used a case series of newborn deaths, which were identified in the HDSS. A case series is a descriptive study that follows a group of patients or cases having a similar diagnosis, or who are undergoing the same procedure over a certain period of time (Kooistra et al., 2009, Grimes and Schulz, 2002). Results of case series can generate hypotheses that are useful in designing further studies, including randomised controlled trials (Brighton et al., 2003). The primary limitation of a case series is its lack of a comparison (control) group and, hence, no causal inferences can be made about the relationship.

### **Study I: Acceptability of evidence-based neonatal care practices in rural Uganda - implications for programming**

Ten FGDs were conducted as follows: two with younger mothers aged less than 30 years, four with older mothers aged greater than 30 years or with mothers having grandchildren, two with fathers, and another two with childminders (older children who take care of other children) of up to age 13 years. Selection of young mothers and fathers was limited to those having children younger than six months of age in order to ensure that responses would most likely reflect recent/current practices. In addition, we also conducted key-informant interviews (KIs) with six health workers and four traditional birth attendants (TBAs).

Villages were selected for interviews from both near (5 km or less) and far (10 Km or more) from Iganga general hospital to represent the rural-urban divide. Using guidelines from the research team, community leaders identified participants for the FGDs, and district leaders of health services identified health workers and TBAs for the KIs. Pre-tested checklists guided discussions about the acceptability and barriers to adapting practices within the continuum of care approach (Marsh et al., 2002, Kerber et al., 2007, Tinker et al., 2005) with special focus on ANC, intra-partum care, and postnatal care for the mother and the baby, as well as to home visits by a volunteer to promote improved care during pregnancy, delivery and in the postnatal period. Participants were asked to present their own experiences and actions, or otherwise to describe general attitudes.

In this study, I led the conception, development of the tools, the collecting of data, the supervising of the field process, as well as the data analysis and writing of the reports/manuscripts.

### **Study II: Socioeconomic differences in uptake of newborn care practices**

This was a population-based cross-sectional study among women with a baby aged 1-4 months (n=414). Socio-demographic and household SES information were collected in a separate survey a year earlier. The tool was pre-tested among 25 mothers attending a postnatal clinic at the local hospital. Mothers who had had a stillbirth or a neonatal death were not interviewed for

this study. Quality assurance of data was through daily assessment by a supervisor; in cases of error or incompleteness of data, corrective measures were implemented immediately.

In this study, I oversaw the conception, the development of the tools, the data collection, and I supervised the field process. I also analysed the data and I also was mostly responsible for the writing of the reports/manuscripts. Active data collection was conducted by the HDSS field assistants and entry by the HDSS data entry department.

### **Study III: Delays leading to newborn deaths**

In the Iganga/Mayuge HDSS, whenever a death was reported, the verbal and social autopsy questionnaire was administered to a close caregiver of the deceased by one of three trained native interviewers. Sixty-four newborn deaths were investigated covering the period January 2005-December 2008. A health facility survey was conducted in each of the 16 major public and private health facilities serving the HDSS, which included a general hospital. Data were collected on physical infrastructure, staff inventory, and on the presence of essential and desirable equipment for newborn care. Finally, knowledge on maternal and newborn care was assessed by using a self-administered questionnaire adapted from one used for a similar study (Harvey et al., 2007). The assessment was conducted among 52 health providers selected proportionally to represent level of care.

Two experienced, practicing physicians independently reviewed each death and assigned cause of death using a hierarchical approach (Baqui et al., 2006). Whenever there was a disagreement, they met to review the case, and if agreement was reached, the diagnosis was accepted as the definitive cause of death. However, if this was not possible, the cause of death was coded as undetermined. Our modified model defined delays as follows: Delay 1, which is the delay in recognising illness and the need to seek medical care, included any newborn baby who died at home or where it took more than 12 hours to seek outside care; Delay 2, the transport delay, included newborn babies whose care givers expressed problems with getting transport; and Delay 3, the delay in receiving quality care, included delay in receiving or failure to receive quality care at a health facility (as judged by the audit physician).

In this study, I led the conception of the study design and the development of the methodological tools, I oversaw the data collection, supervised the field process, as well as the data analysis writing the reports/manuscripts. Data collection was performed by the HDSS field assistants and entry by the HDSS data entry department.

### **Study IV: Perceptions and care of preterm babies at home and at health facilities**

Qualitative methods are conducive for understanding the concepts and perspectives of different groups within a community, by enabling them to express their lived realities (Pope C, 1995, Eng E, 1990). Three different methods were used in this thesis to triangulate findings: participant observations (Mays N, 1995), focus-group discussions, and in-depth interviews (IDIs). Fieldwork

took place in two sub-counties in each district. The respondents for each method are shown in Table 5:

**Table 5: Respondents/subjects and methods**

Method of data collection	Number of subjects/interviews/groups
Health facility observations	16 health facilities
In-depth interviews	n = 30
Community health workers (CHWs)	9
Traditional birth attendants (TBAs)	2
Mothers of preterm babies	10
Fathers of preterm babies	6
Grandmothers of preterm babies	3
Focus group discussions	
Health workers	1 FGD (six midwives/nurses)
Men	1 FGD (8 men)
Women	1 FGD (10 women)

A neonatal midwife from a tertiary hospital worked in health units for one month while also observing health workers, caregivers and events to find out about behaviours and interactions using a semi-structured checklist, and this midwife also recorded both peculiar and mundane activities and observations into a field diary (Mays N, 1995). She spent one day in each of the lower level health facilities, and the remaining two weeks in the general hospital, where most births and deaths occur.

IDIs were conducted with 11 CHWs (3 community drug distributors, 2 breastfeeding peer educators, 4 safe motherhood volunteers and 2 TBAs).

Ten preterm babies were identified from among 42 preterm births recorded in the hospital over a 6 month period (these had complete records regarding physical address), and their mothers were traced at home for interviews. Three mothers of preterm babies could not be traced, so only seven of the selected ten from the hospital were eventually interviewed. Three mothers of preterm birth infants, which occurred at home, were identified by community members for interview. We also interviewed six fathers and three grandmothers of preterm babies. Finally, we conducted three FGDs, one for midwives in the hospital and two in the community with parents, but not necessarily with experience of giving birth to or caring for a preterm baby (one FGD for men and one for women), to get general community perceptions. Towards the end of each community FGD, participants were shown pictures of a mother practicing 'kangaroo mother care' (KMC) in order to assess knowledge, perceptions and acceptability.

In this study, I led the conception and development of the tools, the collecting of data and the supervising of the field process, as well as the analysis of the data and writing the reports/manuscripts.

### 2.3 DATA ANALYSIS

In study I and IV, analysis of the in-depth interviews, key informant interviews and FGDs used content analysis. Transcripts were first read several times to get an overall picture, and then meaningful units were coded, condensed and categorised into broad themes (Graneheim and Lundman, 2004). In study I, barriers to care-seeking were characterised according to the three delays model, which includes delays in problem recognition and deciding to seek care, delay in reaching the health facility, and delay in receiving care once at the health facility (Thaddeus and Maine, 1994). Relevant quotes were extracted and some were presented verbatim.

In study II, socioeconomic status was derived using principal component analysis. The assets used were the same group of context-specific assets as were used by the Uganda Bureau of Statistics for the Uganda Demographic Health Survey (Uganda Bureau of Statistic (UBOS) and Macro ORC, 2007).

Households were classified into wealth quintiles as most poor, very poor, poor, less poor, or least poor using an asset based index derived by scoring the first principal component. Equity was assessed by comparing households from different wealth quintiles on key practices.

Using the following twelve ANC/ENC practices, the mean and median number of practices accessed by the mother/newborn was computed: ANC, tetanus toxoid, antimalarial use during pregnancy, HIV test, and insecticide treated net (ITN) use, anemia drugs, clean birth, facility delivery, safe cord care, optimal thermal care, good breastfeeding, and ITN after birth. The following composite outcome variables were then created: (i) Good cord care (defined as use of a clean cutting instrument to cut the umbilical cord plus clean thread to tie the cord plus no substance applied to the cord); (ii) Optimal thermal care (defined as baby put skin-to-skin at birth or wrapped at birth plus first bath after 6 or more hours); and (iii) Good neonatal breastfeeding (defined as initiating breastfeeding within the first one hour after birth plus baby given no supplements at all in the first month of life). These composite variables were then dichotomised to Yes (all practices present) or No (one or more practices missing).

The data were then subjected to standard descriptive analysis. Chi-square statistics were performed to compare the levels of each of the dependent variables with the explanatory variables. A multiple logistic regression model was constructed for each dichotomised outcome variable using all of the explanatory variables which were significant at bivariate analysis at a p-value of 0.05 or less after confirming absence of multi-collinearity between the independent variables.

Study III was not powered for statistical significance testing, and data were therefore subjected to standard descriptive analysis. The mean knowledge assessment score was calculated by marking each participant out of 100, and then dividing the total by the number of health workers assessed.

## **2.4 ETHICS**

Ethical approval for all studies was given by the Uganda National Council for Science and Technology following review by the Institutional Review Board of Makerere University School of Public Health. In study III, because verbal and social autopsy (VASA) is culturally sensitive, interviews were conducted 4-6 weeks after a death occurred in order to allow a period of mourning as per local customs. In preparation for VASA, one of the HDSS supervisors visited a home of the deceased to prepare the family for interview. Interviewers were recruited locally and trained to respect cultural issues. Verbal informed consent was sought and obtained from all participants. To reduce on the discomfort of narrating the circumstances surrounding a death of a family member, plenty of time and breaks would be allowed when necessary. In all four studies, all moderators and interviewers were experienced, and their minimum education was to diploma level (for moderators) and twelve years of formal education (for interviewers).

In the above section, I have summarised the research methods used in the thesis. Next I summarise the results of each of the four studies, highlighting the most important findings.

### 3 RESULTS

#### 3.1 ACCEPTABILITY OF EVIDENCE-BASED NEONATAL CARE PRACTICES (I)

##### **Newborn care practices are acceptable to community members, but are inadequately promoted**

The essential neonatal care practices include having a supervised delivery, appropriate breastfeeding, cord care and warm care. We found that, except in a few cases, these practices are generally acceptable to the community, but are inadequately practiced, mainly because they are not promoted.

##### a) Antenatal care and birth preparedness practices

Few women reported attending four ANC visits during pregnancy. The reasons given for this included knowledge barriers and service delivery gaps, cultural and traditional beliefs and practices, as well as financial constraints. On the other hand, TBAs were perceived as effective caregivers, since they provided herbal medicine, and were perceived as more mature providers with 'better' personalised care and accessibility than other health providers.

In Busoga (the study area), ANC attendance is called "*okunhwa obulezi*", literally translated as "*drinking medicine*". Thus, within the community ANC is associated with being "ill". Consequently, only women who feel "*ill*" attend ANC visits, and when they do so they expect to get a lot of medication. For instance, intermittent presumptive treatment (IPT) of malaria with Fansidar is one of the key interventions used to reduce malaria in pregnancy and to improve maternal and foetal outcomes. However, when women get only three tablets of Fansidar (the appropriate treatment), they get frustrated, as was reported in one FGD:

*"Yes, I was given three Fansidars and they are at home. I came back quarrelling. I went for ANC for assistance but by giving me only three tablets, how were they helping? Three tablets only! Yet I explained my condition in detail".* (FGD, Young Mothers)

Antenatal and birth preparedness delays are summarised in Table 6 in accordance to the three delays model (Thaddeus and Maine, 1994).

**Table 6: Acceptability and barriers to evidence-based newborn care practices as stated in focus group discussions**

<b>Recommended Newborn practices</b>	<b>Perceived acceptability</b>	<b>Barriers to the practice</b>	<b>Remarks</b>
Cutting the cord with a clean instrument	+++++	<ul style="list-style-type: none"> <li>- Difficult in home deliveries</li> <li>- Poor birth preparedness</li> </ul>	<ul style="list-style-type: none"> <li>- Usually a new razorblade is used</li> </ul>
Maintenance of warmth	+++++	<ul style="list-style-type: none"> <li>- Lack of money for baby clothes</li> </ul>	<ul style="list-style-type: none"> <li>- Some mothers improvise with their own used clothes</li> </ul>
Delayed bathing	+	<ul style="list-style-type: none"> <li>- Belief that babies are born “dirty” and with blood</li> <li>- Belief that babies who are not bathed “smell” bad</li> <li>- Mothers prefer that visitors find babies clean</li> <li>- Health care workers promote early bathing</li> <li>- Belief that early bathing prevents infections</li> </ul>	<ul style="list-style-type: none"> <li>- Babies bathed on day of delivery and thereafter an average of three times a day</li> <li>- Wiping the baby with a wet cloth could be an alternative</li> </ul>
Exclusive breast feeding	+++++	<ul style="list-style-type: none"> <li>- Colostrum not perceived to be good for the baby</li> <li>- Perceived lack of milk in the breast at birth</li> </ul>	<ul style="list-style-type: none"> <li>- Babies given water and/or glucose at birth</li> </ul>
Practicing clean cord care	++	<ul style="list-style-type: none"> <li>- Belief that substances applied to cord help it heal fast</li> <li>- Cultural practice of seclusion till cord falls off</li> <li>- Health workers encourage do not encourage dry care</li> </ul>	<ul style="list-style-type: none"> <li>- Mothers are under pressure for cord to heal so that they can return to routine chores</li> <li>- Health workers encourage application of salty water and spirit</li> </ul>
Postnatal check up for newborns at health unit in the first week	+++++	<ul style="list-style-type: none"> <li>- Practice not promoted by health system</li> <li>- Lack of money for transport</li> <li>- Lack of transport facilities</li> </ul>	<ul style="list-style-type: none"> <li>- Health workers think this will add to their already big work load</li> </ul>
Postnatal check up for newborns at home by a volunteer in the first week	+++++	<ul style="list-style-type: none"> <li>- Identifying new deliveries difficult</li> <li>- Motivating volunteers</li> </ul>	<ul style="list-style-type: none"> <li>- Community expects drugs at home</li> </ul>

Key: The crosses reflect the degree of acceptability of the practice, 1 + to 5 +

b) Delivery care practices

Women reported that they prefer to deliver in health units, but they usually do not because of barriers such as the expensive *maama kits* (a birth-preparedness package with basic necessities for delivery) required in health units for delivery, labour starting at night in absence of transportation, and inaccessible health units that are often closed at night. Other perceived barriers were health worker rudeness, corrupt tendencies and absenteeism from work.

Given such barriers to accessing the formal health system, the possibility of easier options was considered. For example, receiving service based on some form of credit from TBAs in order to offset delivery expenses was described:

*“Usually, the labour pains begin at night. For all my four children, the labour pains began late at night at around 2.00 o’clock. But still, I would get up immediately and look for a health worker where to go. Sometimes the pains start when I don’t even have any money, so I request my neighbour to help me with a bicycle and they take me. Now in my preparation bag for delivery, I usually put a good gomesi [dress], so after delivery, if I am not able to pay, I leave that gomesi behind with her [TBA] until I can pay”* (FGD, older mothers).

c) Newborn care practices in the postnatal period

The newborn care practices deemed acceptable to the community included: maintenance of warmth and cleanliness, exclusive breast feeding and skin-to-skin contact at birth. However, the recommended evidence-based practices of delayed bathing and putting nothing on the umbilical cord met strong objections from both the community and health workers, as babies are believed to be born ‘dirty’, with a ‘bad smell’, and as such needed to bathe so as not to feel “uncomfortable”. Early bathing of newborns is a common practice among health workers, TBAs and the community.

*“My babies are usually born dirty, so it is a must for me to bathe the baby immediately I am discharged on that same day of giving birth”* (FGD, Older mothers).

However, women were agreeable to the suggestion to wipe the baby with a wet warm clean cloth instead of early bathing. In general, respondents were not aware of the need for postnatal health care attendance, except for the immunisation of children.

d) Acceptability of home visits by a community volunteer

All participants welcomed the proposed intervention to improve care of mothers and newborn babies through home visits to households by community volunteers during pregnancy and in the first week after delivery.

*“It is a very good suggestion, we accept, we are overjoyed, eh”*, (FGD for young mothers. They all clapped because they were happy with the idea).

*“We are very happy about it because trained people would be paying us a visit to establish whether mother and baby are fine or not”* (FGD, Older mothers).

In summary, this study shows that although evidence-based practices are acceptable, a few are not. In addition, the study shows that currently, newborn care practices are not well promoted or practiced. This study forms a basis for understanding the low uptake of newborn care practices which is the focus of the study II.

### **3.2 SIMILAR LOW UPTAKE OF ESSENTIAL NEWBORN CARE PRACTICES AMONG THE POOREST AND LEAST POOR (II)**

In general, there were low levels of coverage of the desired practices. A total of 46% of the respondents delivered in the hospital or in a health unit, 26% delivered in private clinics (most informal with unqualified staff and poor infrastructure) and 28% at home or with a TBA. Cord cutting was done mostly by use of a razorblade (67%) of which 11% were reused, and only 28% reported to have used cord scissors. About half of the mothers put substances on the cord (such as powder, surgical spirit, salty water, or lizard droppings).

To keep warm, 86% babies were immediately wrapped, but skin-to-skin (STS) care was almost non-existent (2%). Early bathing was the norm, with 56% of the babies bathed within the first 6 hours, 82% within the first 12 hours, and almost all during the first 24 hours. Although all babies were breastfed, only about half were initiated within the first hour of birth, with 41% initiating within 1 - 6 hours. Other feeds besides breast milk including cow's milk, plain water, sugar or glucose water, gripe water and tea were given to 35% of babies in the neonatal period, contrary to recommendations.

#### **Uptake of packaged newborn care practices is poor in all socioeconomic groups**

When assessed as composite outcomes, newborn care practices of safe cord care (38%), good neonatal feeding (57%), and optimal thermal care (42%). We found that poor cord care was driven mainly by putting substances on the cord; poor thermal care by early bathing and no STS practice; and poor breastfeeding by giving feeds other than breast milk.

Table 7 shows the independent predictors of safe cord care. Multiparous mothers were less likely to have good cord practices when compared to primiparas (OR 0.5, CI 0.3 – 0.9); and so were mothers whose labour began at night compared to those whose labour began during day time (OR 0.6, CI 0.4 – 0.9). Although significantly more mothers in the high SES delivered in health facilities ( $p < 0.000$ ), we found that place of delivery did not predict any of the ENC practices assessed.

**Table 7 Logistic models with safe cord care practices as dependent variable versus all independent variables having significant chi-square values in bivariate analysis**

Variable	Univariate Unadjusted		Multivariate Adjusted*	
	OR	95% CI	OR	95% CI
<b>Maternal Age</b>				
<19	1		1	
19-25	0.52	0.24-1.11	0.68	0.31-1.51
26-30	0.47	0.21-1.03	0.62	0.26-1.47
>30	0.89	0.41-1.93	1.19	0.48-2.95
<b>Parity</b>				
1	1			
2-4	0.44	0.25-0.76	0.45	0.25-0.79
>4	0.68	0.40-1.13	0.57	0.30-1.08
<b>Time labour began</b>				
Day	1			
Night	0.66	0.44-1.01	0.61	0.0 -0.94

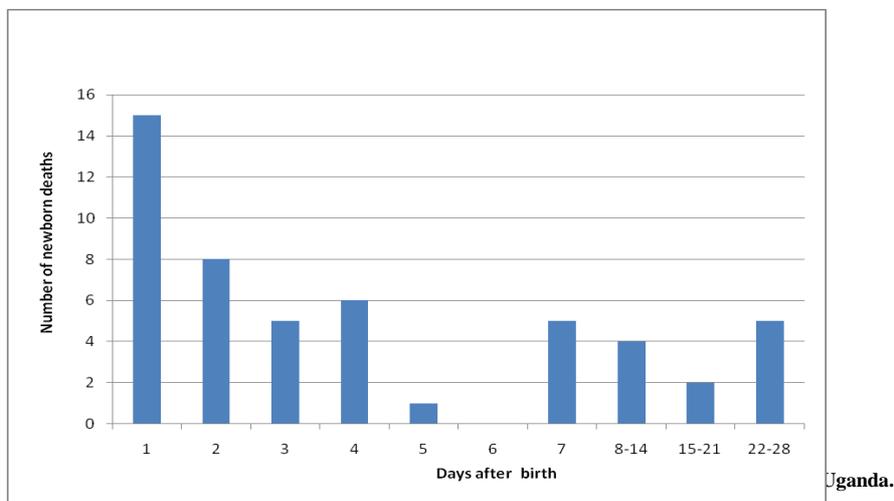
\*Adjusted for maternal age, parity and time labour began

\* p for the whole model = 0.003

In summary, the study findings show that the current uptake of newborn care practices is very low among both the poorest and the least poor; this is independent of where the babies are delivered. In the study III, I report findings of an investigation of the care-seeking process of babies who died and the care they received.

### **3.3 NEWBORN BABIES DIE CLOSE TO TIME OF BIRTH DUE TO CARE-SEEKING DELAYS (III)**

Of the 64 newborn deaths investigated, 37% (24/64) had been born in a hospital or a health centre, 23% (15/64) in a private clinic and 39% (25/64) at a TBA, at home or on the way to hospital. Of these deaths, 47% (30/64) occurred within the first 24 hours after birth and 78% in the first week, and only 22% occurred in the remaining three weeks of the neonatal period (Figure 6). The median age at death was two days (IQR 1-4). During the same period, most births were reportedly conducted by a trained health worker (58%, 37/64). Twenty deaths (33%) occurred either in a hospital or a health centre, 8 (13%) in a clinic, with the majority (54%) dying away from a health facility (TBA, at home or on the way to hospital).



**Figure 6: Distribution of newborn deaths by day after birth in Iganga/Mayuge DSS, eastern Uganda**

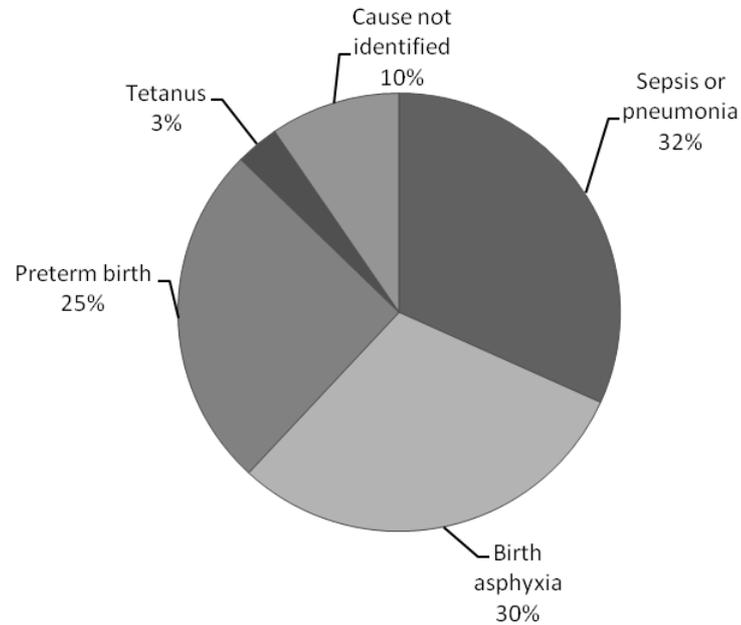
**Problem recognition/decision to seek care outside the home and poor quality health facility care are barriers to care**

The leading causes of death were sepsis or pneumonia (31%), birth asphyxia (30%) and preterm birth (25%) (Figure 7). Delay in problem recognition/deciding to seek care outside the home (Delay 1) was the greatest contributor to deaths (50%, 32/64). Most newborn babies who died had started being unwell during or immediately after birth (57%, 36/64), and were unwell for a short period, with the median duration of illness being two days (IQR 1-6). Care-seeking was generally delayed, with the median duration to seeking care from outside the home being three days from illness onset (IQR 1-6 days).

The second major contributor to newborn deaths was delay in receiving quality care at the health facility (Delay 3) (30%, 19/64). A total of 53% (9/17) newborns that were taken outside the home for care reportedly made contact with a qualified health worker, but five caretakers went to drug shops and one to a spiritual leader.

Surprisingly, the transport delay to a health facility (Delay 2) was found to be a main contributor to only 20% (13/64) of newborn deaths. A second delay was identified as being a contributor to 22% of the newborn deaths investigated.

The major causes of death by main contributing delay were as follows: Delay 1 - sepsis or pneumonia (32%) followed by birth asphyxia (22%); Delay 2 - birth asphyxia (46%) followed by sepsis or pneumonia (31%); Delay 3 - preterm births (37%) followed by birth asphyxia (32%).



**Figure 7: Primary causes of newborn deaths**

#### **Health facilities lack readiness for newborn care**

Health facilities had just about half of the minimum Ministry of Health recommended qualified health workers, and almost all lacked the basic newborn equipment, drugs, supplies and an effective referral system. For instance, only 44% (7/16) of health facilities had a delivery kit, 44% (7/16) had a neonatal weighing scale, and only 6% (1/16) had a neonatal resuscitation kit.

Overall, in the knowledge assessment, participants were correct for only 58% of the questions across the maternal and newborn care continuum (Table 8). Medical assistants/clinical officers had the best mean score (63%), followed by registered midwives (61%), enrolled midwives (56.5%) and enrolled nurses (50%). Participants were correct mostly for questions on ANC (65%), followed by intra-partum care (52%); the least correct answers were on newborn/postnatal care (31%).

**Table 8: The level of health worker’s knowledge on selected maternal and newborn topics**

<b>Topic of assessment</b>	<b>Knowledge score (%) n=52</b>
Infection prevention	42
Use of partograph	56
Active Management of Third stage of labour (AMTSL)	58
Newborn care	31
Pregnancy-induced hypertension	39
<b>Overall average score</b>	<b>58</b>

In summary, the findings here show that delays at home (problem recognition and deciding to seek outside care) and health facility related delays (delay in getting treatment) were the major contributors to newborn deaths in the study setting. Study IV investigated the context in which at risk babies, such as preterm births, are cared for (either in the home or at health facilities), and the capacity to provide care and the opportunities for improvement.

### **3.4 PERCEPTIONS AND CARE FOR PRETERM BABIES (IV)**

In general, both community members and CHWs are able to recognise preterm babies. In the Lusoga language, various labels are applied to preterm babies including *musondole*, *empuna* and *akabulaku*, which translate respectively as ‘a baby born before birth’. The “months” of pregnancy was a common way for fathers, mothers and grandmothers to recognise preterm birth.

*“We identify it from the months. If the baby is born before nine months, we say that aa-ah, it is a premature. Here in our community, men and women try hard to count months from conception to birth. So it comes so easy to know that it is a premature”.* (FGD, men)

The following are some of the features community members use to identify preterm babies:

- The small size of the baby
- Failure to open eyes
- Wrinkled skin
- Weakness portrayed by a faint cry or inability to suckle
- Paleness of the skin, similar in appearance to “newly born rats”

The available CHWs were programme-specific, e.g. breastfeeding peers, community drug distributors or safe motherhood volunteers. Generally, we found that the CHWs were not active due to cessation of the vertical programmes which had introduced them.

TBAs are occasionally involved in the care of preterm babies, who they identify by using features such as ‘baby at birth is very small’, ‘not able to suckle’, ‘skin is wrinkled’, and ‘inability to open eyes at birth’. Like the fathers, the TBAs said that such babies are called “*empuna*”, meaning “a

*baby who came very early*". TBAs reported that when they realise they have helped deliver a preterm, they often give advice on care which includes keeping the baby warm and clean, and feeding.

We found that CHWs were not knowledgeable on STS care or KMC, but once we described the procedures, they showed willingness to promote them, if trained. Possible problems to the promotion of KMC practice at community level were mentioned in the FGDs and included: fear of hurting the baby because 'the cord is still fresh'; women needing to work yet 'the baby has to be in the chest all the time'; and the perception that KMC is tiring.

*"It is tiresome because day, night, day, night, you can even become sick. You can even start bleeding again,"* FGD women.

In general, respondents believed that if well treated, preterm babies could survive, and mothers reported that they treat these babies in the same way as other babies. However, some mothers were fatalistic:

*"I wished that I had had a miscarriage instead of delivering this preterm, it would be better. I never thought that this baby would survive; I thought that it would die any time,"* IDI, Mother of a preterm baby.

#### **Care for preterm babies at community level**

We found that a number of the practices for preterm babies at household level were not appropriate. Generation of warmth was improvised through covering and wrapping of babies in many clothes, lighting lamps and charcoal stoves placed under the baby's bed, and hot water jerry cans or plastic bottles put in close proximity to the baby. Mothers with experience of caring for preterm babies mentioned several challenges they face (Table 9).

*"Time came and I said that paraffin was expensive and my neighbours advised me to always put hot water in a plastic jerry can and always put it under the bed of the baby in order to provide most warmth",* IDI, mother of preterm baby.

In addition, mothers were also advised by health workers to delay bathing babies for several weeks or to use warm wet wipes, while other mothers indicated that the baby must be bathed immediately.

*"They start bathing it immediately the child is born",* IDI, Father of preterm baby.

The use of cooking oil on the baby's skin is common, and is even promoted by health workers with the belief that it 'makes the skin strong'. The notion of "lack of breast milk at birth" was very common in the community. Thus, the use of prelacteals, especially sugar water or cow's milk, was common.

**Table 9: Opportunities, perceived complexities and challenges in the care of preterm babies in Iganga and Mayuge districts, Uganda**

<b>Respondents+/level of care</b>	<b>Opportunities</b>	<b>Challenges</b>
Hospital/health facilities	<ul style="list-style-type: none"> <li>- Provide ANC and delivery care</li> <li>- Referral sites for preterm care</li> <li>- Source of advice on care</li> <li>- Willing to implement STS and KMC</li> <li>- Have some qualified staff</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of adequate access to care</li> <li>- No space, equipment or drugs for preterm care</li> <li>- Staff not trained in preterm care</li> <li>- STS and KMC not promoted</li> <li>- Lack of protocols and guidelines</li> <li>- No postnatal care and follow up services</li> </ul>
Community health workers	<ul style="list-style-type: none"> <li>- Available in communities</li> <li>- Have some knowledge on preterm care</li> <li>- Some promote maternal and newborn care</li> <li>- Some ability to identify preterm babies</li> <li>- Willing to promote maternal/newborn care</li> </ul>	<ul style="list-style-type: none"> <li>- Not coordinated nor supervised/facilitated</li> <li>- Limited knowledge on care for preterm babies</li> </ul>
Community/household members	<ul style="list-style-type: none"> <li>- Some ability to identify preterm babies</li> <li>- Willing to adopt essential newborn practices such as STS and KMC</li> </ul>	<ul style="list-style-type: none"> <li>- Potentially hazardous care practices</li> <li>- Some are fatalistic</li> <li>- Limited knowledge</li> <li>- Burden to women</li> <li>- Poverty and poor house structure</li> <li>- Limited male involvement</li> <li>- Some negative beliefs, customs and attitudes</li> </ul>

In summary, findings in study IV revealed that community members have some knowledge of features that could correctly be used to identify preterm babies. Care practices for preterm babies at community and health facility levels are inadequate. Health facilities lack capacity for preterm care in terms of health workers' skills, basic equipment and drugs. However, community members and CHWs stated that they accepted the introduction of preterm practices, such as skin-to-skin and kangaroo mother care, which is an opportunity for introduction of programmes for preterm care.

In the foregoing section, I have summarised key findings from each of the studies I – IV. In the next section, I put the findings into the perspective of the conceptual model, and relate the discussion to designing future newborn interventions, with special focus on the local ('glocal') context. In the discussion, when referring to the model, the key words will be put in italics. The discussion section ends by highlighting methodological considerations of the four studies, and then the conclusions and recommendations for both policy/programmes, and future research.

## 4 DISCUSSION

This thesis explores both preventive and curative care for newborn babies, at home and in health facilities, as well as related care-seeking delays contributing to newborn deaths in two districts of Uganda. Most evidence-based newborn care practices were acceptable to community members, however exceptions do exist (I). Newborn care practices were of poor quality (I, II and IV) and coverage was low across all socio-economic groups (II). Delays in problem recognition and decision-making (Delay 1), together with poor quality care at health facilities (Delay 3) were found to be the major delays related to newborn death in this setting (III). Most preterm babies are cared for at home, however, care practices are not only inadequate but also potentially harmful (IV). A number of mothers are using powder and antiseptics for the cord, sugar or glucose water for initiation of feeding (I, II and IV) and bottles to feed babies. Health facilities lack capacity (in terms of skilled staff, equipment, drugs, protocols and supplies) for newborn care. However, the acceptability of most newborn care practices is an opportunity to improve newborn care in the two districts. These findings have important policy and programmatic implications for informing the design and delivery of evidence-based newborn interventions in Uganda, and other similar settings.

### 4.1 POOR COVERAGE AND QUALITY OF NEWBORN CARE PRACTICES

#### Low coverage of newborn care practices

The overall level of coverage of newborn care practices was low when assessed as composite outcomes (II). Of newborns, 46% had a facility delivery, and when assessed as composite outcomes only 38% were judged to have had good cord care, 42% had optimal thermal care, and only 57% were considered to have had adequate neonatal feeding (II). The low coverage levels of composite outcomes were contrary to that of some individual practices. For instance, good cord care as a composite outcome had a coverage of only 38%, and yet use of a clean instrument to cut the umbilical cord (85%) and clean thread to tie the cord (90%) were high, but no substance applied to the cord was low (51%). The trend was similar for optimal breastfeeding and good thermal care. Thus, coverage of some practices might be high when assessed as individual practices, but quite low when evaluated as composite practices. These findings imply that, put together, i.e. assessed as composite outcomes, the majority of newborn babies are not accessing adequate preventive practices. Thus, in terms of the conceptual framework, the *prevent* aspect is quite weak.

The quality of newborn care practices was not influenced by place of delivery (II), which suggests that newborn care practices are not adequately promoted by health providers. These findings differ from those reported from rural Uttar Pradesh (Baqui et al., 2007), where it was found that ANC and skilled attendance were associated with clean cord care and early breastfeeding.

The low level of coverage of safe cord care was mainly due to putting substances on the cord; poor thermal care due to early bathing, and poor breastfeeding due to giving feeds other than breast milk (II), meaning that even at health facilities evidence-based newborn care practices are not being promoted. Although not recommended, about half the respondents applied substances to the umbilical cord. Implementation of clean cord care is very important in preventing early neonatal infections (World Health Organization. Maternal and Newborn Health/Safe

Motherhood., 1998). Regarding prevention of hypothermia, the findings show that STS care was generally not practiced, and yet it is recommended for all babies (Darmstadt et al., 2006). Whereas it is recommended that babies should be bathed no earlier than 24 hours after birth, most babies were bathed within the first 12 hours, and almost all within 24 hours of birth. Maintaining good thermal care at birth is crucial for preventing hypothermia, hypoglycemia and neonatal infections. Indeed, studies in Uganda have shown that even if it is a tropical country, hypothermia at birth is common (Bergstrom et al., 2005, Byaruhanga et al., 2005), and thus promotive STS care as a preventive practice for hypothermia is indicated even for babies in these settings.

The findings indicate that although almost all mothers breastfed their babies, about half of the infants were not breastfed within the first one hour (II) as is recommended (World Health Organization. Maternal and Newborn Health / Safe Motherhood Unit., 1996), thereby putting these neonates at an increased risk for death (Edmond et al., 2006). In addition, more than one-third of respondents reported that they gave feeds other than breast milk in the neonatal period. A study by Engebretsen et al. conducted in eastern Uganda (Engebretsen et al., 2007) found that only 7% of infants were exclusively breastfed by age three months. In other words, both their study and ours show that as early as the neonatal period, over one-third of infants are not exclusively breastfed.

The low coverage of essential newborn care practices means that the *prevent* aspect of care for the newborn is weak, and needs strengthening.

Since newborn care practices such as cord care can only be considered as appropriate, if cord cutting and tying are performed cleanly, and cord care is dry, i.e. nothing is put on the cord, then it makes sense to evaluate them as composite instead of as individual outcomes. Unfortunately, many studies reporting newborn care practices only report coverage of individual practices (Sreeramareddy et al., 2006, Baqui et al., 2007, Khan et al., 2009). It has been proposed that a co-coverage analysis is a useful compliment to the analysis of coverage for separate interventions, since it takes into consideration the delivery of several interventions (Victora et al., 2005a). A number of new analyses on coverage and equity of child survival interventions are now using composite or co-coverage indicators (Victora et al., 2005a, Fenn et al., 2007). The author of this thesis proposes that future evaluation studies of newborn care practices should report both individual but also composite indicators.

### **Similar low coverage of newborn care practices across all socioeconomic grouping**

Study II is one of the first studies to assess coverage of composite newborn care practices by socioeconomic status. The coverage of composite newborn care practices did not differ between the least poor and the poorest, i.e. coverage seemed not to be modified by socioeconomic status. This was despite good physical access to health facilities. Usually, mortality is higher and coverage is lower among the poorest (Hosseinpour et al., 2005). Further, it has been documented elsewhere that universal interventions often reach the least poor first and the poorest later (Bryce et al., 2003), but this was not the case here.

There are several possible explanations for the lack of differences in coverage across socioeconomic groupings. First, in the study setting, there were no specific programmes promoting newborn care in the study districts during the previous five years (and therefore even the least poor were not accessing the desired care practices). Secondly, it may be that SES

classifications in quintiles as based on assets (such as type of material used for floors in houses or as possession such as a bicycle) may not classify people in relation to newborn care practices. The study lacked power to find a difference in composite newborn care practices by SES.

#### **4.2 ACCEPTABILITY OF EVIDENCE-BASED NEWBORN CARE PRACTICES AT COMMUNITY LEVEL**

##### **Acceptable but not well practiced newborn care practices**

Most of the globally recommended newborn care practices were acceptable to community members (mothers, fathers, grandmothers, grandfathers and CHWs) (I and IV), but they were not well promoted by providers which might be the explanation for the low coverage. For instance, few women reported attending ANC four times (I, II and IV), as recommended (Carroli et al., 2001, Villar et al., 2001). One of the reasons for this could be a poor perception of ANC. Further, it is common in the study setting to refer to attending ANC as “*okunhwa obulezi*”, which is literally translated as “drinking medicine”, and pregnant women attend ANC mainly when they are ‘unwell’ or ‘ill’ or to get an ANC card (I). In reference to the theory of reasoned action (TRA), the *attitude* towards ANC attendance more than once is negative because of *low evaluation of perceived impact/benefit*. Such findings seem to suggest that health providers may not be promoting ANC and newborn care practices in ways that enable communities to comprehend the importance of these services, communities may perceive the quality to be low. To improve attitude (and possibly as one of the ways to improve ANC attendance four times), there might be a need to redefine ANC from “drinking medicine” to caring for a healthy pregnancy, so the community members can see the *perceived impact*. Attendance of ANC four times was deemed acceptable by community members if access barriers such as transport and requests for illegal payment as made by health workers, were minimised (I). In terms of the TRA, these barriers form the *external factors*, and require addressing.

On the other hand, the majority of women reported that they would prefer to have a health facility delivery, although in practice women often did not manage, mainly because of a number of barriers, including costs, distances, rude health workers and the challenges of accessing health care at night (I, II and IV). These barriers are what constitute the so called *external factors* in the TRA model. Put together, these external factors resulted in a *moderate intention* of women to deliver from a health facility. Such challenges need to be addressed. These same challenges were identified in two recent published reviews as contributing to care-seeking delays for delivery care (Bhutta et al., 2009, Gabrysch and Campbell, 2009).

Apart from delayed bathing and putting nothing on the umbilical cord, community members had a *positive attitude* to other immediate newborn care practices, such as STS and early initiation of breastfeeding. However, despite the positive *attitude* and acceptability, these practices were not well followed by caregivers (I, II and IV). Although many caregivers had a positive attitude toward early initiation of breastfeeding, they also had the perception that women ‘lack’ breast milk at birth, which helps to explain the low intention for breastfeeding at birth. Such caregiver perceptions were behind the initiation of breast milk substitutes (I, II, and IV). In addition, postnatal care, which is a critical practice for saving newborn lives (Darmstadt et al., 2005), was poorly practiced in the study setting and caregivers were not aware of its importance except for the immunisation of children or when a baby is ill (I). However, mothers placed high value on and had acceptability to postnatal care, because, according to them, they “usually get

complications after birth”. As such, in terms of the TRA model, postnatal care has high *outcome expectancy* among community members, and a package delivered to meet the community’s needs would most likely have high uptake.

### **Practices deemed less acceptable by community members**

Among the globally recommended evidence-based newborn care practices, a few were deemed to be less acceptable to most community members (I and IV). For example, although the WHO guidelines recommend that nothing should be put on the cord (World Health Organization. Maternal and Newborn Health/Safe Motherhood., 1998), and that bathing of babies should be delayed, this was not deemed acceptable many community members or health care providers because of various perceptions or barriers. The perceived need for early bathing was of the newborn is strong in this community. Some of the reasons given included a belief that putting substances on the cord helps the cord to “heal fast”, and that “babies are born dirty” or that mothers expected “visitors to find the baby clean” (I). Thus, in terms of the TRA, mothers have an *expected behaviour* and are expected to oblige with the *perceived social normal* of bathing the baby.

A study in Tanzania showed that many communities support the notion that the umbilical cord is thought to make the baby vulnerable to witchcraft, and great care is therefore taken to shield both the mother and baby from bad spirits until the cord falls off. Such forms of ‘protection’ include applying drugs, cow dung, and powder to help heal the cord. Bathing also plays a role here, and babies are bathed early, sometimes with cold water (Mrisho et al., 2008). Studies in South Asia have reported similar findings, including unhygienic cord cutting and care, as well as early bathing (Baqui et al., 2007, Kesterton and Cleland, 2009, Moran et al., 2009, Fikree et al., 2005, Sreeramareddy et al., 2006).

The implication of these findings is that interventions to promote dry cord care and delayed bathing must focus on both the individual (to allay *expected behaviours*) and the community (to address *social norms*).

The finding that some globally recommended evidence-based newborn care practices might not be acceptable, and are therefore not promoted or implemented at the community level, raises the issue of “fit” and whether or not “evidence-based” interventions actually fit in the local implementation context (referred to as ‘glocal’). There is no “one size fits all” to neonatal survival (Knippenberg et al., 2005), and interventions proved effective in one setting, may, in another setting, need to be preceded by local adaptation so as to be ‘tailored’ to the local context before being scaled up (Bhutta et al., 2008b, Bhutta et al., 2008a, Haines et al., 2004). This is important for understanding the “black box of implementation” (Peterson, 2010, Victora et al., 2005b) A compromise of practices might be needed, such as wiping instead of early bathing, or applying a safe substance to the umbilical cord (such as chlorhexidine) (Mullany et al., 2006, Mullany et al., 2008b).

### **4.3 DELAYS CONTRIBUTING TO NEWBORN DEATHS**

As pathological causes, sepsis or pneumonia, followed by birth asphyxia, and then preterm births were the leading causes of death overall, as reported elsewhere for low income countries (Lawn et al., 2005b, Lawn et al., 2006). However, as ‘social causes’ of deaths, when the modified three

delays model (Thaddeus and Maine, 1994) was applied, the findings showed that 50% of newborn deaths were mainly related to *recognise delay* (Delay 1 or delay in illness recognition and deciding to seek outside care), and 30% were due to *treat* (Delay 3 or poor quality care at health facilities), while 20% were due to *access or transport problems* (Delay 2). The delay to *seek* seemed not to be a major problem in the study setting due to a relatively good physical access to health facilities (III), which may not be the same across Uganda. Together, delays *recognise* and *treat* contributed to 80% of the newborn babies who died. These findings on the contribution of delays to newborn death differ from those in a Tanzanian study by Mbaruku and colleagues, which was one of the first studies to apply the three delays model to perinatal death (Mbaruku et al., 2009). The latter reported that most newborns died as a result of the third delay; however, Mbaruku's study only collected data from the hospital and did not include older neonates (>1 week).

### **Delay 1: Delays in problem recognition and delays in deciding to seek care**

Of the newborn babies who did not die on the day of birth, most deaths occurred following *delays* at home. The majority were sick for at least three days before care was sought outside the home (III). Nearly half of the at-home deaths resulted from sepsis or pneumonia (III). According to the original model by Thaddeus and Maine (Thaddeus and Maine, 1994), delays at home could be a reflection of problem recognition or a delay in deciding to seek care. Given the fact that newborn babies are very vulnerable, a *delay* of three days which we found before *seeking* care outside the home is grave, and such sick newborns may not be helped by weak health facilities.

A recent ethnographic study in Ghana found that mothers might not be able to recognise serious illness in their newborns, and they also often do not seek care outside the home even when they do *recognise* serious illness (Bazzano et al., 2008). It seems that even when parents are made to *recognise* the need to *seek* outside care, decision-making can be problematic. An intervention trial in Bangladesh, in which CHWs conducted intense surveillance of sick newborns, identified two challenges especially for young neonates: reaching neonates within the first two days after birth and 'parental compliance with advice to seek outside care' (Darmstadt et al., 2009). Studies in older children conducted in the same setting (Rutebemberwa et al., 2009d, Rutebemberwa et al., 2009b), and elsewhere in Uganda (Peterson et al., 2004), have identified challenges to care-seeking as mainly related to cost.

From the above it is clear that efforts to improve newborn survival in Uganda must address 'Delay 1' delays related to recognition and decision-making.

### **Delay 2: Delay in reaching a health facility**

Of newborn babies who died, 20% were related to Delay 2, and the main cause of death was birth asphyxia (II). The seemingly low contribution of transport delays to babies who died may be explained by the fact that the study setting had generally good physical access to health services, and availability of bicycles and motorcycles as means of referral was good. However, for transportation to be effective, it must also be of the right quality. A limitation of the second delay as originally presented by Thaddeus and Maine (Thaddeus and Maine, 1994) is that it does not call for assessing the quality of transportation. Transport of seriously ill children has been identified as an important but neglected issue in global health (Duke, 2003). There is evidence that morbidity and mortality of critically ill patients are much reduced if specially trained teams

availed transport and delivered life-saving treatments (Britto et al., 1995, Vos et al., 2004). However, such transport facilities cannot be met by the current bicycle and motorcycle services in the area. As such, transport for seriously sick children needs to be improved.

### **Delay 3: Delay in receiving quality care at a health facility**

In total, 33% of newborn deaths were attributed to health facility-related delays and resulted mainly from prematurity (37%), followed by birth asphyxia (32%) (III). These findings support those of study IV, which also showed care for newborn babies to be of poor quality at health facilities. The health facility assessment conducted in the area (III and IV) showed inadequacy in the number of qualified providers. Further, available providers lacked knowledge about managing newborn babies (III). A knowledge assessment on care during pregnancy, delivery and postnatal care (III) showed the average score to be low, especially on questions related to newborn care (31%). These findings are similar to those reported elsewhere in low income countries (Eriksson et al., 2009, Harvey et al., 2007). The health facility assessment also showed a general lack of basic newborn equipment, drugs (injectable ampicillin and gentamycin), supplies and an effective referral system. For instance, only 44% (7/16) of health facilities had a delivery kit, 44% (7/16) had a neonatal weighing scale and only 6% (1/16) had a neonatal resuscitation kit. Thirteen percent of newborn deaths occurred in small private clinics; where capacity to manage the newborn was also very weak. Similarly, a recent study of Kenyan hospitals also found that these did not have a capacity to manage sick newborn babies (Opondo et al., 2009).

Thus, in terms of the three delays model, a lack of skilled staff, protocols, drugs and equipment coupled with weak management often lead to *treat delays* in providing quality care for sick babies as well as other newborns at risk of death, such as those with birth asphyxia or prematurity. The risk of deaths for newborn babies is made even worse when one considers that in Uganda, it is currently presumed that sick newborn babies can only be managed at higher level health facilities. This effectively means that because of policy regulations, the lowest level of health facilities (HC-IIs) are not allowed to have the basic newborn drugs and equipment, and their role in care is thereby limited to the initiation of treatment prior to referral. Such limitations remain, despite the fact that well documented, evidence-based constraints to care-seeking for sick children to attend health facilities have been identified (Hildenwall et al., 2009b, Kiguli et al., 2009, Pariyo et al., 2009, Rutebemberwa et al., 2009c, Rutebemberwa et al., 2009d, Rutebemberwa et al., 2009b, Hildenwall et al., 2008, Kiwanuka et al., 2008, Kallander et al., 2008). Thus, reducing the *treat delay* by bringing qualified staff, equipment, antibiotics, supplies and guidelines to improve newborn care at health facilities of all levels is critical for newborn survival in this setting.

## **4.4 PERCEPTIONS AND CARE FOR PRETERM BABIES**

Study IV demonstrated several missed opportunities for health promotion activities to improve care of preterm and other low birth weight babies. Mothers were doing their best to care for preterm babies, but care practices were of poor quality and potentially harmful (IV). At community level and in health facilities, including the general hospital, no STS or KMC was practiced. To keep warm, e.g. babies were wrapped in many clothes. Although most preterm babies were managed at home, care practices were of poor quality. For instance, and in addition to practices already mentioned, mothers reported using hot objects such as jerry cans filled with hot water and charcoal stoves to keep preterm babies warm. Therefore, these mothers perceived preterm babies as needing special care.

Furthermore, information from interviews showed that community members were generally not fatalistic in their attitudes, as was also found in Malawi (Tolhurst et al., 2008). Thus, in terms of the TRA, the mothers had a *positive attitude* towards preterm care, meaning that if health providers took advantage of this opportunity to promote newborn care practices, the chances of them being accepted was likely to be high (high *outcome expectancy*). However, missing was the promotion of desired practices by caregivers. Recent reviews have re-emphasised the importance of implementing interventions to improve the care of preterm births, which is not only the leading direct cause of neonatal mortality, but also accounts for an estimated 27% neonatal deaths every year and is a risk factor for many neonatal deaths resulting from other causes such as infections (Lawn et al., 2006). Providers of health care should take advantage of this perceived positive attitude towards preterm babies by promoting the recommended care practices at both health facility and community levels.

#### 4.5 A NEED TO WATCH A NEWBORN CARE PRACTICES TRANSITION?

Findings in study I, II and IV showed that a number of mothers were putting powder or antiseptics, among other substances, on the cord, and were using a bottle to feed the baby or were mixing/replacing breastfeeding (especially at initiation of feeding) with various substitutes such as glucose or sugar water or honey (I, II and IV). Whether these are replacing other “more dangerous” practices, such as putting cow dung, dust or ash on the cord (as prevalent in the study area in the past) could not be shown in a cross-sectional study. But powder, antiseptics and bottle feeding are relatively new phenomena.

Similar ‘new’ practices have also been reported from Bangladesh (Moran et al., 2009), India (Kesterton and Cleland, 2009) and Tanzania (Mrisho et al., 2008). Moran and colleagues reported that women apply several substances to the cord including talcum powder and savlon (an antiseptic liquid). In addition, initiation of breastfeeding is often done by giving other substances such as honey and sugar water, and the authors suggest that such practices are a consequence of increasing urbanisation (Moran et al., 2009). The Uganda Demographic Health Survey (UBOS, 2006) and a study from western Uganda found that use of pre-lacteals was common even among educated mothers (Wamani et al., 2005). Studies on breastfeeding patterns in low income countries suggest that changes in breastfeeding have been influenced by marketing of formula milk, urbanisation, and the need for women to work away from home (Winikoff and Laukaran, 1989). Thus, applying the TRA, these findings seem to suggest that within a changing environment the practices of mothers may be influenced by *perceived social norms* in which caregivers are *aware of the expected behaviour* and are *willing to comply with such expectations*, that is, they may associate some of these practices with ‘modernity’. If these assumptions are true, then the implication is for a need for interventions targeting the entire population so as to diffuse the *perceived social norms* that are evolving. Here, the example of infant formula replacing breastfeeding is a warning example of how ‘modern’ practice with commercial interests can lead to a practice transition (Howard et al., 2000, Dennis, 2002).

## **4.6 METHODOLOGICAL CONSIDERATIONS**

### **Generalisability and Transferability**

The survey was conducted in only one region of Uganda, a study setting with relatively good physical access to health facilities, meaning that the transport delay elsewhere might be more significant. On the other hand, the relative good physical access to health facilities can be interpreted as meaning that newborn care practices in the study setting might be better than elsewhere where access is much more difficult. While this study was conducted in only one region, some of the findings are generalisable or transferable to other parts of Uganda, especially among other Bantu groups who form the majority of the population.

### **Sample size and sampling bias**

Study I was a population based cross-sectional study in which all mothers with newborn babies 1-4 months were interviewed, i.e. this was a total count, and this helped limit errors of selection bias. A limitation was that the study excluded babies who had died as neonates or who were born as stillbirths. In addition, study III was aimed at trying to offset this limitation by focusing on babies who died but it also excluded stillbirths. More so, by focusing on babies who died, respondents tend to remember the more severe signs, and may not, for instance, have remembered as well the practices around birth. Another limitation is that study III investigated a small number of newborn deaths (n=64). The HDSS update round is done after every six months, and this causes a gap in capturing some events, especially perinatal deaths. A further limitation related to sample size is that of SES. Although we wanted to assess uptake of newborn care practices by SES, the sample size was not large enough to determine differences between quintiles. In addition, we did not have information on other attributes of socioeconomic status such as education level of mothers.

### **Recall bias**

In all studies except study IV, the actual practices could not be verified because data were collected through recall. To minimise recall bias, interviews were limited to only mothers with babies up to four months (II) or to 4-6 weeks after a newborn death (III). Similar studies report recall up to one year after birth (Baqui et al., 2007, Osrin et al., 2002). The study was questionnaire-based, meaning that questions that require a good memory or might be sensitive were more vulnerable to recall bias or to socially desirable answers. However, it is simple events that are more likely to be forgotten (such as what drug a child was given) compared to more serious events (such as a convulsion). In addition, the reproducibility of the answers and measurements could not be assessed for reasons of feasibility.

### **Reporting bias**

Self-reported illness is sensitive to the cultural and socioeconomic milieu (Segall et al., 2002, Gao et al., 2001, Sauerborn et al., 1996). Information collected in studies II and III was based on caretaker reports of preventive practices (II), and on the care-seeking practices that occurred following an illness of a newborn baby (III). As such, there is a question about whether it was “actual practice” or “reported practice”. The caregivers might have reported what they felt the interviewers wanted to hear (Krause et al., 1998, Hildenwall et al., 2009a, Bowling, 2005). To

offset this, data were collected by HDSS field research assistants who had already established a rapport with the local community, and most of them were native, so they had a good idea of the local customs and practices. These field research assistants were not medically trained, and this limited chances of misclassification as a result of an attempt to do medical interpretation. In addition, in study IV, the actual care provided to preterm babies at health facilities was observed by a neonatal nurse.

### **Triangulation**

Triangulation of methods, sources and perspectives is regarded as a pivotal strategy in obtaining authenticity (Angen, 2000). It involves comparing data from different methods, and comparing the perspectives of people from different points of view. In studies I and IV, a triangulation of methods was used, including FGDs, IDIs, KIIs, and actual observation of care provided (IV) to preterm babies. For instance, in studies I and IV, respondents reported care practices which were deemed inadequate (e.g. initiating breastfeeding with sugar water or putting substances on the cord), and some unacceptable, and this was confirmed in study II, where coverage of evidence-based newborn care practices was found to be low.

Respondents also varied from among community members, CHWs and health professionals, which further helped triangulate findings. Findings from studies I and II, which were based on interviews, were further triangulated by actual observation of care (IV) in health facilities. In addition, study II excluded newborn deaths, but this was triangulated in study III, which investigated newborn deaths. Studies I and IV used qualitative methods where selection of respondents was purposive and non-random. However, the purposive nature and use of different respondents allowed for the generation of rich information (Patton, 2002). Using more methods permits a more accurate estimate of the unknown object (Berg, 2001), and there is mutual confirmation of measures and valuation of findings. Researchers included social scientists as well as medically trained.

### **Verbal autopsy and the three delays model**

In paper III, the social autopsy and the modified three delays model was used to assess the care-seeking processes, and treatment actions that occurred prior to each death. The social autopsy tool, adapted from the InDEPTH Network, was not so specific in eliciting delays, and may have led to an under-estimate of delays. Certain aspects of the questionnaire could also have been more specific, especially on care-seeking and referral, and should also have included specific questions on identifying problems of illness recognition and decision-making among caregivers. In addition, we did not assess the actual care provided to each newborn that died, and as a result, information on the contribution of facility-related delays has some limitations. However, we tried to offset this by performing a health facility survey of all facilities in the study area, and also assessed provider knowledge on newborn care. The findings confirmed a lack of capacity to manage newborn babies as health facilities lacked basic newborn equipment, drugs, supplies, and protocols. The social autopsy study also excluded stillbirths, yet they are more often a result of delays in care-seeking than other newborn deaths (Lawn et al., 2009c). The exclusion of stillbirths might have led to underestimation of some delays, especially delays 1 and 2.

### **Reflexivity**

Reflexivity refers to how knowledge is shaped by the researcher and how this is accounted for in the research process (Angen, 2000), especially awareness of the researcher's contribution to the construction of meanings throughout the research process. In fact, the research project was conducted in an area where I was born and grew up, and subsequently practiced medical care as a doctor for nine years. At the time of studies I, II and III, I was still employed by the local district health services, which enabled me to intimately understand the research area, as well as some of the practices. However, the tools were developed by a multi-professional research team, which included national policymakers and were based on similar tools used elsewhere. Of particular note, it is important to add here that the actual field process conducted in studies I and IV were led by social scientists that were external to the study area.

## 4.7 CONCLUSIONS

Based on the findings described in this thesis, the key conclusions are:

- Most evidence-based newborn care practices were acceptable to community members but a few were not deemed acceptable (e.g. delayed bathing and putting nothing on the umbilical cord) (I).
- Newborn care practices are, in general, of poor quality and coverage is low across all socioeconomic groups (II).
- The available health workers lack knowledge and skills to manage newborn babies (III and IV).
- Care for preterm babies at home and in health facilities is generally inadequate and some practices are potentially harmful to babies (IV).
- Among babies who died, the major contributing delays were delay in problem recognition and deciding to seek outside care (delay 1), followed by delay in receiving appropriate care while at health facilities (delay 3), and then the transport delay (delay 2) (III).
- Some mothers put powder or antiseptics on the cord, use a bottle to feed, and mix/replace breastfeeding with various substitutes (I, II and IV).

## 4.8 RECOMMENDATIONS

Since care practices for newborn babies are generally inadequate across all socioeconomic groupings, a universal strategy targeting the whole population that also addresses both care-seeking delays and the major causes of deaths is recommended. At household/community level, the possibility of engaging community members through CHWs, in order to address Delay 1, need to be explored. This could be done initially through tailored promotional interventions or through both promotive and curative interventions, depending on the local context such as hard to reach areas with poor access to health facility care. On the supply, which is at facility level, efforts should focus, among others, on improving quality of care for sick newborn babies, and on management of birth asphyxia and preterm babies. However, efforts should also focus on specifically promoting essential newborn care practices in health units and hospitals. These improvements will entail in-puts such as equipment, drugs, training and protocols for newborn care. A policy shift to give lower level health units and private clinics a role in managing newborn babies may be needed.

The globally recommended neonatal care practices that are based on evidence from other settings, such as Asia, will need to be adapted to the local context before implementation, as some may not be acceptable to community members.

Finally, policymakers need to mitigate a possible newborn care practices transition in which “suboptimal” practices are being replaced with “modern” practices. This can be done through proper training, provision of clear guidelines and support for health workers, and by especially ensuring that health facilities have adequate supplies.

The findings described in this thesis were used to design an ongoing community-based facility-linked newborn intervention that we are conducting in the two study districts (UNEST: Uganda Newborn trial ISRCTN50321130). The study is thus an example of research-to-intervention with possible future implications for programmes and policy, since results and experiences from each stage are constantly fed to policy makers. The UNEST intervention package was designed with national stakeholders based on the Ugandan health system, but was also tailored to identified barriers and delays leading to newborn death. At community level, trained CHWs conduct home visits to promote uptake of evidence-based newborn care practices during pregnancy, and also after birth. In addition, they conduct surveillance for newborn babies with danger signs or for those born at home, and refer to health facilities. At health facilities, health workers have been trained for improved management of labour and delivery, resuscitation of the newborn, provision of essential newborn care, and care for the sick newborn. To ensure sustainability of quality of care, perinatal audit with closing of the audit loop has been added. Some basic equipment and drugs were also supplied, but continuous provision is ongoing through the local procurement system.

### **Recommendations for future research**

- Implementation research on how to reduce care-seeking delays and improve referral and care at home and in both private and public health facilities for newborn babies.
- Implementation research on how to best integrate CHWs into maternal and newborn care in health facility-linked programs, especially the interface with primary level health facilities.
- Explore how information from the combined verbal and social autopsy can feed into district and national programmes to reduce neonatal and stillbirth rates.
- Standardise, validate, and determine the utility of composite newborn care practice indicators in routine newborn evaluations and programming.
- Explore possible emerging newborn care practices, their consequences (including possible effect of cross-integration of old and new practices) and possible mitigation measures.

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