# "We shall count it as a part of kyogero"

# The acceptability of chlorhexidine for umbilical cord care in the cultural context of Central Uganda

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Centre for International Health
Faculty of Medicine and Dentistry
University of Bergen, Norway
2017

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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of Philosophy in International Health at the University of Bergen.

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# Supervisor

Karen Marie Moland

#### **Abstract**

#### **Background**

Over 40% of the 6 million deaths in children under 5 occur in the newborn period. Infections account for a quarter of all newborn deaths. The umbilical cord has been identified as a major route of newborn infections. Application of chlorhexidine on the umbilical cord has been shown to reduce newborn infections and deaths in some settings. Chlorhexidine needs to be applied exclusively to avoid the re-introduction of microorganisms after chlorhexidine application. A randomised controlled trial (RCT) to determine the effectiveness of chlorhexidine application on the cord at birth is currently being implemented in Central Uganda. We conducted a formative qualitative study in the same area to explore the meanings and practices attached to the umbilical cord, and the acceptability of using chlorhexidine only in the care of the cord of the newborn.

#### Methods

The study was designed to inform the design and interpretation of the RCT. The study was composed of two parts. The first part explored the meanings and care of the umbilical cord, while the second part explored the acceptability of chlorhexidine for umbilical cord care. In total, 52 in depth interviews and 7 focus group discussions were conducted with mothers of infants, health care workers, traditional birth attendants and other caregivers.

#### **Findings**

The umbilical cord had a central symbolic position in newborn care. The way it was handled had far reaching consequences for the survival and wellbeing of the baby. At the same time, the cord was a centre of anxiety as a possible gate to illness, but also as a test of fatherhood and a signifier of parental responsibility. Hence, the cord and the way it was cared for played a part not only in the survival of the baby, but also the survival and wellbeing of the household. In this context, *kyogero*, a local herb mix was used and reused several times to bath the newborn and clean it both physically and ritually during the first weeks after birth.

The introduction of chlorhexidine for cord care was accepted as complementary to *kyogero*. While chlorhexidine was seen to have a desirable local effect on the cord itself reducing its foul smell and reducing abdominal colic, it did not facilitate the highly desirable early cord fall off and could not replace the symbolic functions of *kyogero* and its place in securing the overall wellbeing and blessings of the child and the household.

#### Conclusion

The introduction of chlorhexidine for cord care in Central Uganda needs to take the local meanings and practices of cord care into account. Whereas participants were willing to adopt chlorhexidine, they were not willing to abandon the washing of the newborn in *kyogero*. The future success of chlorhexidine use on cord care may depend on negotiations between the health workers and the mothers' decision-making circles on the possibility to defer the *kyogero* bathing until after umbilical cord fall off. In that way both the concern for hygienic cord care and the concern for the wider ritual functions of *kyogero* can be accommodated.

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# **Glossary of Acronyms**

Av Average

CHX Chlorhexidine

DNA Deoxyribonucleic acid

FGD Focus Group Discussion

HC Health Center

HW Health Worker

IDI In Depth Interview

MDG Millennium Development Goals

No Number

RCT Randomised Controlled Trial

SDG Sustainable Development Goals

TBA Traditional Birth Attendant

UN United Nations

VHT Village Health Team

WHO World Health Organization

### Acknowledgements

First, I want to thank supervisors; Professor (s) Karen, Thorkild, James, Marte and Dr. Victoria. Prof Karen Marie Moland, you have showed me the beauty in qualitative research, anthropology and skiing. You instructed and guided me with love and compassion. I will cherish the memories of this journey.

To Dr Victoria Nankabirwa, who is also the principal investigator of the chlorhexidine study, I would love to say thank you so much. Dr Victoria, you planted this question, and I came for the harvest. I hope that the harvest was done to your satisfaction. Thank you so much for allowing me to work in this project and for the continuous guidance throughout the project. In a special way, I would love to acknowledge Prof James K Tumwine who has mentored me for over 8 years. You introduced me to the University of Bergen and you advised me to pursue a Masters degree, an idea that had not crossed my mind. I see it now, but you saw it then. Thank you for your ever-present wise counsel. I am honoured to have you as my mentor and supervisor. I will always strive to think outside the box.

Prof. Thorkild Tylleskär, I am so lucky to have you as my supervisor. You are the only supervisor I have ever seen pick their student from the airport. You are also the only supervisor I have ever seen cook a 5 course meal for his students. You have been there whenever I needed you and have taught me so much. *Webale nnyo*!

To Ms. Marte Haaland, I am so grateful. We have walked this journey together. You were there from the beginning and you are still here, walking tall. God will surely reward you. To the University of Bergen, CIH, thank you so much. I thank Bente Moen, for continuous assistance and the songs she is so fond of. I thank the Anthropology group at the University of Bergen, lead by Karen and Astrid. The administrative staff of CIH, especially Linda Forshaw, Solfrid Vikoren, Gunhild Koldal, Ingvild Hope and Borgny Lavik, you have been the best administrators of this century.

The chlorhexidine study team; Victoria, Halvor, Josephine, Sam, Olive, the study nurses, the study participants, and the various health care workers, thank you so much. A special thank you to Ms Namyalo Florence Jeke for excellent work done.

To the awesome team; Doreen Pamba, Mwila Lundamu, Amalie Boge and Ingrid, you have not only been true classmates but have also been true friends. This is not the end of our journey but it is just the beginning. All my other masters' classmates; Feven, Mengistu, Samuel and Hassan Ali, keep smiling!

To my Parents Mr and Mrs Patrick James Mukunya, Siblings, friends; Job, Peter, Hepzibah and Edward, you make it worth the struggle.

Finally and most importantly, to my Lord, ultimate boss and Saviour Jesus Christ, the Glory goes to you and the victory belongs to you.

ALUTA CONTINUA, VITORIA E CERTA!

## **Chapter 1: Introduction**

#### **Child mortality**

During the period between 1990 and 2015 the number of children under the age of 5 who died globally decreased from approximately 12million to 6 million (1-3). This unprecedented reduction can be attributed to targeted global health efforts, political commitment and global economic development (3, 4). Millennium Declaration and the Millennium Development Goals agenda (5, 6) sparked a worldwide political commitment to development goals, one of which was reduction of child mortality by 2/3 between 1990 and 2015 (1, 3, 6). The political commitment also resulted in increased funding for areas such as child health (7) with an aim of reducing child mortality. A number of strategies were initiated which successfully reduced child mortality. Reduction in infectious diseases contributed the most to the dramatic decrease in child mortality with deaths from pneumonia, diarrhoea, malaria and measles markedly reduced (3). However, the reduction in deaths of children under the age of 5 was not uniform across the various age groups. Most of the reduction in mortality occurred in children in the post neonatal period, that is, children older than 28 days (1, 2). On average, the annual rate of reduction in mortality was 1.2 to 1.4% lower in the neonatal period as compared to the postneonatal period (2). Unlike the under-5 mortality which decreased by 52% between 1990 and 2015, neonatal mortality decreased by 42% and therefore accounted for 2.6 of the 6 million under-5 deaths (3). This slower reduction of neonatal compared to post-neonatal mortality can be seen at the global (2, 7), country (2) and regional level (8). Due to this disproportionate reduction in mortality, over 40% of mortality under the age of 5 years occurs in the neonatal period (first 28 days of birth). In addition, most of these deaths occur in low and middleincome countries, with sub-Saharan Africa having one of the highest mortality rates in the

world at 28 /1000 live births (1, 3). And within these countries, most of the deaths happen among the poorest households.

Fuelled by the success and shortcomings of the Millennium Development Goal era, that was between 1990 and 2015, global leaders unanimously adopted a new set of goals to guide the global development agenda in the period between 2016 and 2030, called the sustainable development goals (9, 10). The third sustainable goal aims to ensure healthy lives and promote wellbeing for all and at all ages. Target 3.2 of the SDGs is to end preventable deaths of newborns and children under 5 years of age, with all reducing under-5 mortality to at least 25 deaths /1000 live births and neonatal mortality to at least 12 deaths/1000 live births (10). For Uganda this is a huge challenge as the current under-5 mortality is approximately 64 deaths/1000 live births and the neonatal mortality is approximately 27 deaths/1000 live births (11). Neonatal mortality is not evenly distributed throughout the country and some regions such as the Eastern region have registered much higher neonatal mortality rates (12). In order to achieve the sustainable development goal target 3.2, the rate of reduction of neonatal deaths has to change. This necessitates looking closely at the biggest contributors to neonatal mortality and addressing their underlying causes. The three largest contributors to neonatal mortality are pre maturity, and intra partum complications and infections (1, 7). Within low and middle-income countries, infectious diseases play an even larger part in neonatal mortality. Most of the deaths due to infections in the neonatal period are preventable. In fact, with the available and known interventions, deaths due to infections have the largest potential for reduction, with 84% of all deaths due to infections thought to be preventable with available low cost interventions (13). This makes infections a very suitable target for interventions to reduce neonatal mortality.

#### **Neonatal infections**

Newborn infections account for about a quarter of all newborn deaths (7). Infections in the newborn period mainly include neonatal sepsis or meningitis, pneumonia, diarrhoea and tetanus. The majority of deaths caused by infections are attributed to neonatal sepsis or meningitis (7). This rather ambiguous classification is because neonatal sepsis and neonatal meningitis present with very similar signs and symptoms and differentiated them (especially in retrospect) is very difficult. Infections also contribute significantly to deaths from other causes such as prematurity (1). Infections are not only a cause of mortality also but have significant neurodevelopment sequelae attributed to them for example cerebral palsy (14, 15) and impaired motor development (16). One of the major routes of infection in the neonatal period is thought to be the umbilical cord (17).



Figure 1: An infected umbilical cord of a newborn

The umbilical cord of is thought to be a major route of infections because of its patent connection to the blood stream of the new born. Research shows that mothers who practice what is called 'clean cord practices' have a reduction in mortality of about 17deaths/1000 live

births (18). In addition umbilical cord infections have been shown to increase the odds of all cause mortality by three and sepsis related mortality by almost 5 (17). As a result, the proper hygienic care of the umbilical cord is recommended to prevent unnecessary complications. Due to the absence of evidence supporting chlorhexidine umbilical cord care in sub Saharan African, the World Health Organization recommends dry cord care for countries like Uganda where most births take place in health facilities and the neonatal mortality rate is less than 30/1000 live births (19, 20). Consequently, the Ugandan Ministry of Health has adopted dry cord care as the national standard.

#### Umbilical cord care

Studies done in Uganda show low levels of uptake of the recommended dry umbilical cord care practice, with most authors quoting an uptake less than 50% (21-23).

These studies show that the recommended practice of dry umbilical cord care is not unanimously adopted, as it conflicts with popular beliefs and cultural practices (24-26). Dry umbilical cord care is thought to delay umbilical cord fall off, and hence a number of substances are put on the surface of the umbilical cord in the hope that the substances will hasten umbilical cord fall off (27).

In addition, in Uganda, as is in many other societies, the umbilical cord carries great symbolic significance (28) and is at the core of many cultural practices. In certain areas for example New Guinea, Perry reports that the umbilical cord is seen as a sister or twin to the child and hence should be carefully kept (29). Studies in various African countries have indicated that the umbilical cord is perceived as a sign of vulnerability, a pathway through which evil spirits gain access to the body (30), and through which wind and other illnesses could access the newborn (31). In Eastern Uganda this is partly prevented by seclusion of newborns until the umbilical cord falls off (32). The moment of cord fall off was treated as the moment the child

ceased to be a newborn (32). Examples of substances applied onto the umbilical cord include; salty water, soot, banana ash, herbs, surgical spirit, powder, ghee, papyrus reeds, saliva, water, butter and vaseline (21-23). These substances vary depending on the country, region and cultural groups studied (31). As to why they are used, some mothers who participated in a study conducted in East, Central and Western Uganda perceived herbs to be superior to the biomedical medicines (27).

Umbilical cord care has been shown to be embedded in larger cultural constructs like rites of passage (33) in South Sudan, and fertility in Zambia (28). Interventions that require behavioural change may be met with resistance particularly when they involve practices that are deeply embedded in cultural constructs. This was witnessed in south Sudan, where a public health intervention which involved giving mothers clean delivery kits, met challenges due to the cultural practices which had to be done around the time of birth (33). Similarly, an intervention concerning umbilical cord care could face challenges if it is thought to conflict with cultural practices. Understanding the symbolism and meanings of the umbilical cord and how these relate to cord care practices, could contribute to the development of guidelines that could be acceptable within the targeted communities (28).

#### Chlorhexidine and the umbilical cord

Chlorhexidine has been advocated for, as an alternative to dry cord care in areas where dry cord care has not been accepted and adopted by the population (25). Chlorhexidine is an antiseptic, which was introduced for use as an umbilical cord care, due to its clinical safety compared to the alternative substances like hexachlorophene, which were demonstrating toxicity in the newborns (34). Chlorhexidine works by reducing the colonisation of the umbilical cord by pathogenic organisms (35). Pathogenic organisms not only cause infection

in the colonised newborn, but they also cause infections in newborns in the surrounding vicinity, probably transported from one newborn to another by health workers (35). These organisms can also cause infections such as breast abscess to the mother (35). Since chlorhexidine works by reducing microbes on the umbilical cord, it should be applied exclusively, that is, nothing should be applied concurrently as these added substances might have microbes and hence confound its efficacy. A substance that clears these organisms should be expected to reduce both neonatal morbidity and mortality. Indeed, application of chlorhexidine to the umbilical cord has been found to reduce the incidence of both newborn infections and newborn deaths in three Asian countries; Bangladesh, Nepal and Pakistan (36-39), countries characterised by high levels of home births. So far, the effectiveness of chlorhexidine remains equivocal in African settings, where studies have shown that use of chlorhexidine slightly reduces omphalitis but does not affect mortality (40, 41). This could be due to the different settings and contexts of Asia and Africa, with Asian countries having a much higher percentage of home deliveries than Africa. The inability to observe a mortality benefit could also be due to the fact that study settings provided a situation where sick newborns were quickly referred for care and hence a lower mortality situation than would be expected in a typical setting (41). Irrespective of these controversies, leading newborn health researchers highlight chlorhexidine use as one of the prioritized interventions for strengthening newborn health (1, 42).



Figure 2: 7.1% liquid chlorhexidine solution

Drawing from such recommendations, the Uganda Ministry of Health is planning to change its policy from dry cord care to chlorhexidine umbilical cord care. The success of such an intervention will depend on whether it is accepted in the communities in which it is introduced. One major anticipated challenge to chlorhexidine umbilical cord care uptake is its association with prolonged umbilical cord fall (35). Most caretakers in both African and Asian settings seem to prefer that the umbilical cord fall off quickly (28, 43, 44). The prolongation of umbilical cord fall off has the potential to discourage caretakers from using it (25, 33, 45). However despite this, some researchers have found chlorhexidine use for the umbilical cord to be acceptable in an African setting (46). The acceptability of behaviour interventions vary from context to context and local belief systems might not be a barrier but,

to the contrary, be very helpful in promoting interventions (47). This was demonstrated in an ethno-medical study by Kendall et al, who argued that promoting oral rehydration therapy as a purgative, which was in line with the way the local population in Honduras explained a type of diarrhoea known as *empacho*, might have resulted into greater success of a diarrhoea prevention program (47). Since most of the evidence demonstrating effectiveness of chlorhexidine has been obtained from studies done in south Asia, in contexts where most births occur at home and with very high neonatal mortality, more research concerning chlorhexidine use for umbilical cord care in sub Saharan Africa settings, which have lower neonatal mortality and high facility births is needed.

#### The chlorhexidine trial

As a result of the inconclusive evidence of chlorhexidine effectiveness from settings outside Asia, particularly Africa, a randomized controlled trial is being conducted in Uganda (clinical trials.gov number: NCT02606565). This trial tests the effectiveness of a one-day application of 7.1% chlorhexidine on the umbilical cord on reducing the incidence of neonatal sepsis. Since most of the previous studies have been done in community settings, and yet recent surveys show that over 70% of births in Uganda are taking place at health facilities (11), this study is situated within health centres and recruits newborns on the first day of life. Research nurses/midwives apply the chlorhexidine solution on the umbilical stump of the newborn, in research offices located within the hospital facilities, very close to the maternity wards after obtaining informed consent. Mothers' of the newborns are then advised not to put any substance onto the umbilical cord after chlorhexidine is applied. This is done in order to discourage application of harmful substances. The study aims to recruit approximately 4000 newborns. The newborns are followed up for 28 days and are examined on days 1, 3, 7, 14 and 28. The newborns in the control arm receive the standard of care, which is supposed to be

dry cord care but is usually modified to include salty water in most health facilities. This is the first time chlorhexidine is being used in the study area and the participants do not have prior exposure and experiences with chlorhexidine.

The acceptability of chlorhexidine in Uganda in general is not known, but needs to be explored to guide future plans to scale up chlorhexidine use in this population. In addition this information will guide the interpretation of the concurrent chlorhexidine trial, assessing the effect of chlorhexidine on prevention of neonatal sepsis.

### Problem statement and justification

Neonatal mortality is unacceptably high in low and middle-income countries. One of the major causes of neonatal mortality is newborn infection. Newborn infections often start from the umbilical cord, especially when unhygienic practices are being carried out. Cord care recommendations by the World Health Organisation (WHO) are by neonatal mortality and place of delivery. As a result, the WHO recommends dry umbilical cord care in Uganda. However, two studies that together covered the Eastern, Central and Western regions of Uganda reported that dry umbilical cord care was unacceptable to many of the mothers and the health workers that participated. Chlorhexidine offers a safer alternative; in addition to discouraging unhygienic umbilical cord care practices, it has been shown to reduce umbilical cord infections and deaths in Bangladesh, Nepal and Pakistan. The effectiveness of Chlorhexidine in African settings remains uncertain. Interventions designed to promote newborn health have often faced challenges to scale up. This is because perceptions about what constitutes good newborn care and the customary practices to strengthen newborn health and survival are embedded in broader cultural conceptions about the human body, health and illness, kinship and belonging. The success of any intervention will consequently depend on its acceptability and adoption within the sociocultural context it is being introduced.

The chlorhexidine trial offered a unique opportunity to study the acceptability of chlorhexidine. This was the first time chlorhexidine was going to be used in this setting and we could then explore participants' experiences. In addition, the Ugandan Government was planning to introduce recommendations, promoting chlorhexidine umbilical cord care and information from this study would be of benefit in the process of planning and implementation of the new guidelines.

## **Research question**

How do caretakers and health workers perceive the use of chlorhexidine on the umbilical cord in the cultural context of newborn care in Mukono and Kampala districts of Central Uganda?

## **Objectives**

- To explore the meanings attached to the umbilical cord
- To identify umbilical cord practices in community settings
- To explore experiences with using chlorhexidine for umbilical cord care among caretakers and health workers
- To explore perceived benefits and opportunities to the use of chlorhexidine for umbilical cord care
- To explore perceived challenges and barriers to the use of chlorhexidine for umbilical cord care

## Theoretical perspectives

In this study I will borrow from three theoretical perspectives when reporting and discussing the findings. These theories were chosen after data collection to act as aids in the interpretation of the findings. I will use Mary Douglas' 'purity and danger' (48) to understand the symbolism of the umbilical cord in newborn care and how meanings are constructed around the umbilical cord. I will also use Douglas' concepts to try and understand the handling of the cord and how different the umbilical cord is perceived depending on its location. I will continue to draw upon the work of Douglas' and use her concepts of risk to explain the relationship between the biomedical risk and the broader concept of danger in newborn care. Finally, since the ultimate goal of chlorhexidine research (if it is shown to be efficacious) is to have it available for every newborn, I will use Everret Rogers' theory of the diffusion of innovations to examine chlorhexidine's potential for diffusion and scale up in the community.

## Dirt as 'Matter out of place'

In the book 'Purity and Danger (1966)' (48) Mary Douglas speaks of the concept of dirt being matter out of place. She argues that what we label as dirt in one context may not be considered dirt in another context. For example shoes are not inherently dirty but we consider them dirt when they are placed on a dining table (48, 49). To explain why the idea of shoes on top of the dining table is disturbing, Deborah Lupton eloquently explains 'dirt is found to be offensive and disturbing because it threatens the 'proper' separateness of the individual from other things and people, it bespeaks intermingling, the breaking down of boundaries' (49). In other words, something becomes dirt when it crosses the boundaries that have been placed by a particular society. Societies come up with boundaries (or rules) that should not be transgressed as a form of self-preservation (48). Since societal margins mark boundaries, they

are treated as dangerous or potentially dangerous and a high level of control is exerted on them (49). In a similar way, body orifices are treated with anxiety, and this could simply be a mirror response from the broader society (49). Mary Douglas argues that ritual protection of bodily orifices could simply be a symbol of social preoccupations about exits and entrances (48). Substances that don't fit in one bounded category or substances that seem to be ambiguous are seen as threatening. One potential way of dealing with such is removing them (49). An example cited by Mary Douglas is the discomfort caused by sticky substances, which we often find discomforting, possibly because they are ambiguous in their physical state as neither clearly solid, nor liquid. I utilise these perspectives to understand how the meaning attached to the umbilical cord changed in relation to different boundaries of the body.

#### Risk and blame

When the word risk is used, Mary Douglas says that it often refers to danger. Mary Douglas argues that risk is a concept that is culturally constructed and not only based on an individuals' cognitive assessment (50). To quote Mary Douglas in her book Risk and Blame on page 12 *Anger, hope, and fear are part of most risky situations. No one takes a decision that involves costs without consulting neighbours, family and work friends. These are the support groups that will help if things go wrong (50).* A refusal to take the given advice exposes oneself to blame. When examining risk from a communal perspective, Mary Douglas states that moral and political perspectives are very essential. The political perspective includes who is to be blamed for a particular risk. Elaborating on this communal rather than individualist notion of risk, while quoting Mary Douglas' work, Deborah Lupton quotes; 'A community uses its shared, accumulated experience to determine which foreseeable losses are most probable, which probable losses will be most harmful, and which harms may be

preventable' (49). I will use this understanding of risk, to try to understand why study participants that included trained midwives, used *kyogero* despite its potential risk.

#### **Diffusion of innovations**

Everret Rogers, in his book 'Diffusion of Innovation', attempts to explain the pathway of adoption of a new innovation. Diffusion can be loosely defined as the social process through which information moves from individual to individual (51). An innovation is an idea perceived as new (51). It is very important to note that diffusion is a social process. Rogers explains that in every society, there are five categories of people based on how quick they adopted an innovation. Listed in descending order of the rate of adoption, they include: innovators, early adopters, early majority, late majority and laggards (51). Within the early adopters is a special category of people called the opinion leaders. These have great influence over the adoption of the innovation by a community (51). The society looks upon these opinion leaders for an opinion. They tend to be respected and trusted members of a society, and similar to the average community member in many ways. Knowing the leaders and their opinion about a product can then be a rough predictor to the future success of an innovation. Rogers introduces a term re-invention defined as the level to which an innovation is modified during the process of diffusion (51). It represents a form of active participation in the process of innovation and increases the level of comfort that the users find with the innovation. However, it is a process the change agents may have little or no control over. Characteristics of the product itself can determine whether it will be adopted. Five characteristics are mentioned: relative advantage, compatibility, complexity, trialability, and observability (51). Relative advantage is how much better the new product is perceived compared to existing options, the better an innovation is compared to existing products, the faster it will be adopted (51). Compatibility is how well an innovation is perceived to blend into the existing sociocultural values, previously introduced ideas and with client needs. The easier it blends, the faster the rate of adoption (51). Complexity is how difficult to use, an innovation is perceived to be; the more difficult the less the adoption rate (51). Trialability is how readily users can experiment with the innovation, the more they can experiment with it, the better (51). Observability is how visible the change the innovation brings is visible to others, the more visible the faster the adoption rate (51).

I will use the five characteristics above gauging how well the study participant's perceived chlorhexidine. I will also use the characteristics of opinion leaders to determine which group of people could qualify as opinion leaders for umbilical cord care in this study setting.

## **Chapter 2: Methodology**

#### **Design of the study**

This qualitative study was conceived as an effort to inform the design and interpretation of a randomized controlled trial (RCT) that aimed to determine the effect of chlorhexidine on umbilical cord infections. The study had two parts, the first part started in June 2016, which was one month before the start of the RCT. This was planned so that its preliminary findings could inform the final designing stage of the RCT. Within this rather limited time, the formative qualitative research was able to identify the presence of a popular herbal mixture called *kyogero*, which was not included in the original questionnaires of the RCT. The second part started in August 2016, which was one month after the start of the RCT. This timing was chosen because participants spent approximately 1 month in the RCT and we wanted to interview participants who had just exited the RCT. In this part, we conducted exit interviews with mothers who had completed the trial. Both parts of the study ended in January 2017.

#### Formative qualitative research

In this study a qualitative study was designed along a randomised controlled study assessing the effect of chlorhexidine. Designing a qualitative study alongside an RCT helps develop interventions that are focused on the participants being studied (52). Qualitative research can inform the RCT before, during and after the RCT (52). Before an intervention starts, qualitative research can inform the quantitative researchers on what to ask and how to ask it (53). During the intervention, qualitative research can help modify the way an intervention is being conducted. After the intervention, qualitative research helps in interpreting the findings from the intervention. Since the RCT was involving an intervention, scale up of the

intervention would require knowledge of how the participants perceived the intervention and acceptability of the intervention (51).

Qualitative research has been observed to greatly inform complex processes (53) like behavioural change interventions. When studying new interventions like chlorhexidine use on the umbilical cord, qualitative research offers a lot of insight (53). In our case chlorhexidine was a new product in the area. So we set out to study "what" practices were being carried out and "how" people would perceive chlorhexidine. A qualitative design is the preferred design in studying the "what and how" and the "why" of a phenomena (54). We also wanted to explore the way people perceived umbilical cord care and chlorhexidine usage from their viewpoint. What meaning did they make out of the umbilical cord? What was their understanding of chlorhexidine cord care? To answer such questions, a qualitative design was the most suited. The design of this study borrowed from phenomenological strategy of inquiry, which is best situated to explore meaning and essence of a phenomenon (55).

In addition, qualitative research allows us to modify our methods and data collection tools as we progress with the study (54). This study was designed to explore concepts that we had no prior knowledge of and hence needed a design that allowed as much flexibility as possible. Due to the inductive nature of a qualitative design, it can often produce new ideas that could be studied further with other methodologies. This study gave birth to a new idea, which we had not thought of, or envisioned during the planning of the study. The idea was the possibility of chlorhexidine reducing infantile abdominal colic. Though having no known biomedical basis, reduction of umbilical colic was a repeated theme in our qualitative interviews and we decided to investigate it further using other methodologies.

On the other hand, conducting a qualitative study along an RCT made us encounter a new challenge. Since we conducted exit interviews on mothers who were finishing a trial experience, it made it difficult to separate the participants' experience of the use of chlorhexidine from their participation in the trial itself. For example, when participants spoke positively about their experience with the use of chlorhexidine, what they may have liked most might have been the provision of a free service by very compassionate study staff. This could have led to a mix up of the trial participation experience, and the chlorhexidine experience. However, we did not have a way out of this as, chlorhexidine was only being used under study settings, at least by the time of the initiation of our study.

In this study, we used in-depth interviews as these allow participants to share their experiences and understanding at a deeper level (56) and focus group discussions to collect group level perceptions and cultural norms (57). A known disadvantage of focus groups is that participants fear to voice out their individual views and only express favoured group views. To minimize this risk, we typically conducted FGDs, after a sufficient number of indepth interviews had been conducted, and divergent issues were always included on the FGD guide. Another data collection method we used was video recording. This was used to provide a detailed description of some aspects of the study and to act as a way of validation. Video recording gives the readers a real life view of some of the complex sub-themes that arose. The video will be available on special request. These various methods were also used as a form of triangulation to increase the trustworthiness of our findings (58).

The study was conducted in both health facilities and in the community. Three health facilities were chosen because they were the sites of the RCT. The health facilities had their own health staff that differed from the health staff the RCT hired.

## **Study setting**

The study was conducted in Uganda, which is a multi-ethnic country. Our study was located in 2 districts in Central Uganda: Mukono and Kampala (green on Figure 3), which are mainly, composed of the Baganda people.

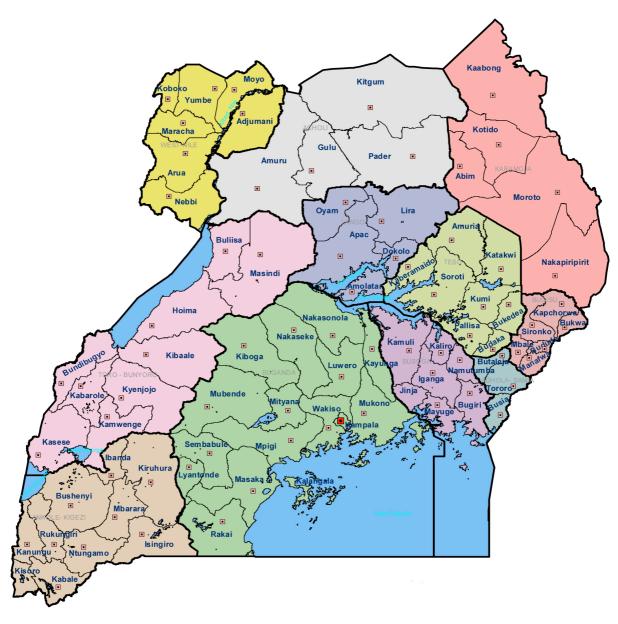


Figure 3: Map of Uganda showing Central Uganda in green and the study districts Kampala and Mukono far right in the green area (source-United Nations OCHA)

The Baganda inhabit the central region of Uganda, and constitute the largest ethnic group in the country (59). Kampala district is the capital city and Mukono district is a neighbouring peri-urban district. The districts were chosen because they were the sites of the randomized controlled study. Mukono district was purposively chosen for the community component of the study, because I expected to find more individuals who were knowledgeable about the meanings of the various umbilical cord practices.

The health facilities where the study was based were mid-level, a step or two from hospital status. Facilities that are one step below hospital status conduct both normal and Caesarean section deliveries, whereas facilities that are two steps below hospital status only conduct normal deliveries. In Kampala, we conducted our studies at two health centres. Kitebi Health Centre IV, which is one step below hospital status and hence conducts both normal deliveries and Caesarean sections. The second health centre is Kawaala Health Centre III, which is 2 steps below hospital status and hence only conducts normal deliveries and refers mothers in need of Caesarean section. In Mukono we conducted our study at a health facility we shall not disclose for reasons of confidentiality, because of the health centres' association with Traditional Birth Attendants who are outlawed as I later explain.

We conducted our community study from Nsaba village (pseudonym), which is a neighbouring village to the health centre we studied in Mukono. This village is in a semi-rural setting with most people living as subsistence farmers with small businesses to supplement their farm produce. In the effort to have all pregnant women deliver from health care facilities, the President verbally outlawed Traditional Birth Attendants (TBAs) in Uganda (60). The Ministry of Health also terminated a previous working relationship with traditional birth attendants (61). The traditional birth practice is hence considered illegal and participants

in such a practice are liable to prosecution (62). However they remain very popular within the various villages, and the communities protect them and continue to consult them (61). The ban was declared because they were blamed for the delay of women seeking care from the approved facilities, as mothers first consulted them and hence an increase in maternal deaths (61). Health workers also attributed a number of complications to traditional birth attendants; as they lacked the necessary knowledge, skills and equipment to conduct safe deliveries. Due to the perceptions above, there exists a tension between health workers and traditional birth attendants in most places in the country. Unlike most of these places, health workers at the health centre we studied have chosen a different approach. These health workers decided to collaborate with TBAs in the nearby village and use them as health promoters and referral agents to the facility. TBAs are recruited into the village health team, and are usually the point of entry into these communities in matters concerning health. As a result, most TBAs in Nsaba village also act as members of the village health team. The village health team, a group of members chosen by a community who act primarily as health promoters, distributors of health related materials and registers of health related events like births. Nsaba village was chosen because of this unique relationship between the health workers and the TBAs. However, despite this relationship a tension and an air of suspicion persist. We experienced this in the field with some TBA's refusing interviews when contacted on phone, but agreeing when contacted by our gate keeper, mama Taba (pseudonym) a middle aged woman with over 20 years experience acting as a TBA.

#### Study participants

Study participants were divided into two groups based on the two parts of the study. The first part was to explore the meanings and practices associated with the umbilical cord. The second

part was to explore the acceptability of chlorhexidine for umbilical cord care. In total we conducted 52 IDIs (In Depth Interviews) and 7 FGDs (Focus Group Discussions).

#### Part one: meanings and practices surrounding the umbilical cord

I conducted 22 in-depth interviews and 3 focus group discussions. These were conducted exploring umbilical cord care practices. We interviewed 10 mothers with infants, 3 fathers with infants, 4 healthcare workers and 5 traditional birth attendants most of whom doubled as village health team members. Mothers of the infants were identified from the community and interviewed either at their homes or at our gatekeeper's home, according to the mothers' wish. We asked our gatekeeper (who was both a TBA and village health team leader) to locate mothers in the community who had recently delivered and were residents of the area. Mothers were interviewed because they were the persons who spent most time with the newborn and were the primary persons responsible for taking care of the newborn in this setting.

We also interviewed some fathers because we expected them to be involved in the care of the newborns and hence knowledgeable about cord care. We decided to interview fathers after interim analysis, when we seemed to be reaching data saturation, as an attempt to discover more and varying themes. We soon learned they were not as informed as we had earlier thought and abandoned them in favour of the grandmothers. The fathers of the infants interviewed were found at the area health facility having come to escort their partners. This was done having failed to find fathers at their homes during our visits to the mothers' homes. We also interviewed healthcare workers we found at the local health centre. They included the head of the maternity ward and 2 other healthcare workers in the maternity unit. We chose to recruit health workers from the maternity unit because they are the ones responsible for

umbilical cord care at the facility. One extra health care worker was recruited from the private clinic in the community we studied. We interviewed her because some mothers reported getting advice on how to care for the cord from her.

We also interviewed TBAs because they are the alternative maternal and neonatal health care providers in the communities. As already stated, the village where we conducted our research is special, since there is a health relationship between the local health facility, the local area leaders and the TBAs. However the TBAs are still sceptical of unfamiliar people inquiring about their practices. Due to this, we recruited TBAs by a variant of snowball sampling, by first identifying their leader who then introduced us to the rest of the TBAs. The rest of the participants were recruited by purposive sampling, we purposed to recruit participants who were very knowledgeable about the content areas in question and could express their opinions confidently. We also purposed to have some participants who varied from the normal participants, for example we purposed to have some teenage mothers and elderly mothers.

Interviews were conducted face to face at calm and private settings away from distractions in order to increase the comfort of the interviewee and hence collect more accurate data (56). In both parts of the study, participants were recruited until the point of saturation (54) was reached. We determined that we had reached saturation when no new themes were being derived from subsequent interviews. It was possible to determine the saturation since the analytical process was an on-going process, taking place alongside the data collection. We also determined saturation by varying our participants and determining whether any new themes came up. An example is the interviews of fathers in the first phase of the study. This was not initially planned but after noting that we were not deriving any new themes we thought fathers might have differing views. We conducted three FGDs; two involved young

mothers and one involved elderly women. The interviews with the young women were conducted at the health centre facilities whereas the one of the elderly women was conducted in the community at our gatekeeper's home. The FGDs with young women were conducted at the health facility premises, because we wanted to recruit women who had children less than one year of age. Having already completed the community IDIs it became extremely difficult to get enough eligible women for FGDs. We opted to recruit the women for FGDs from the health facility when they showed up for postnatal follow-ups or immunization schedules.

#### Part two: Acceptability of chlorhexidine for umbilical cord care

For the second part of the study, we conducted 30 IDI's and 4 FGDs. All the participants in this part had an experience with chlorhexidine through participating in the RCT. We interviewed 18 mothers as they exited the RCT on day 28. This was done to enable us interview participants with fresh experiences that they could easily remember, but who had had some time to deliberate on the essence. These mothers were chosen both purposively and conveniently. Mothers were interviewed because they spend the most time with the newborns. We aimed at interviewing participants with rich experiences and also to include maximum variation in our sample. The variation was on the basis of ethnicity, education, caretaker roles and age. We also interviewed 8 study nurses. The study nurses are nurses who were recruited specifically to work with the RCT. They are different from the health centre nurses and they are not involved with the work of the health centre. Most of these nurses had worked for an average of 6 months with the study before our interview, and which we deemed as an adequate period to observe chlorhexidine use, but also short enough not to have forgotten previous practices. We purposed to recruit all nurses who had worked with the RCT by December 2016. Apart from one study nurse who was on a prolonged sick leave, we managed to interview all the study nurses. Two TBAs were also given chlorhexidine bottles to use on

babies in their practice and these were also interviewed. These TBAs also act as village health team members and hence it was legal to offer them these health products. We also interviewed a father and a grandmother of a baby who had received the chlorhexidine intervention. This was done in order to enrich our data by soliciting views from various participants. This was also important as a check of data saturation in order to determine whether new themes emerged from varied participants. These particular participants were purposefully chosen because they had been present from the moment of application of the chlorhexidine and had witnessed the entire process.

**Table 1: Study participant summary** 

	In-Depth Interviews (N=52)	Focus Group Discussions (N=7)
	Mothers-10 IDIs	
Part one	Healthworkers-4 IDIs	Young Women- 2 FGDs
	TBAs-5 IDIs	Elderly women- 1 FGD
	Men-3 IDIs	
	Mothers-18 IDIs	
Part two	Study nurses-8 IDIs	Mothers- 3 FGDs
CHX arm	TBAs-2 IDIs	Study nurses- 1 FGD
	Other Caretakers- 2 IDIs	

Interviews were conducted in a separate room at the RCT facility. The TBA interviewers were conducted in the community. These TBA's were chosen purposively. We also conducted 4 FGDs. We conducted 3 FGDs with mothers exiting the RCT one at each site. The participants were telephoned and invited for the FGDs. We also conducted 1 FGD with the study nurses.

Since we had a small number of study nurses, the FGD participants were the same participants we had interviewed in the in depth interviews.

Table 2: Study participant demographic characteristics

	Average (Av.) age	Av. education level	Av. No*
			of children
Young mothers	24	Secondary	2
Older mothers	52	Primary	6
TBAs	55	Primary	7
Health workers	41	Tertiary	_
Mothers	25	Secondary	3
Study nurses	30	Tertiary	2
TBAs	50	Primary	6
	Older mothers TBAs Health workers  Mothers Study nurses	Young mothers 24 Older mothers 52 TBAs 55 Health workers 41  Mothers 25 Study nurses 30	Young mothers  24 Secondary  Older mothers  52 Primary  TBAs  55 Primary  Health workers  41 Tertiary  Mothers  25 Secondary  Study nurses  30 Tertiary

No\*: Number Av: Average -: Missing

#### **Data collection**

Data was collected from 06<sup>th</sup> June 2016 to 27<sup>th</sup> January 2017. Part one started in June and part two started in August; data collection was done simultaneously after that.

I used a semi-structured interview guide, which was modified as necessary in the course of the study (54). Two separate interview guides were used for each phase. One part was administered to mothers, and another for the health care workers. I also used different topic guides for the group discussions. These tools are attached in the appendix.

To enable me to get a thorough description of individual and group experiences and understanding, I would start the interview with establishing rapport, then asking an openended question, for example "what was done immediately after the birth of your baby?" I would then wait for the participant to initiate the discussion on cord care, and then ask her to elaborate and probe from that point further.

In some instances, where the participant focused on other practices that were not to our interest, I would rephrase the question to "what was done to your baby's umbilical cord immediately after deliver?" This would then kick off our conversation in the right direction. Subsequent questions were asked following an interview guide that would be reconciled after each field day, to make it more applicable for subsequent interviews. Due to the open-ended nature of the interview guides, many interesting themes came up outside our area of interest. For example, mothers and TBAs expressed concern for the increasing level of obstetric violence by health-workers. They also noted a fear of tears and episiotomies, which they say are being witnessed more often from deliveries by health-workers. They noted that such issues are discouraging women from seeking facility deliveries. Such and similar issues were not analysed, and are not presented in the result section of this thesis.

I had not interacted with any mother prior to the interview as a staff of the Randomised Controlled Trial. This was important to reduce the fear from mothers that giving any unfavourable answers would affect their future relation with the study research assistants. The interviews usually lasted between 20 to 80 minutes. Since I speak the local language in the area, I conducted most interviews in *Luganda*, the local language and a few in English. A moderator and one note taker led the focus group discussions. FGDs were usually conducted

in *Luganda*. Participants were briefed on the main purpose of the discussion and emphasis was placed on inter participant discussions and confidentiality (57).

IDIs and FGDs cannot capture the entire phenomenon, multiple cues are given by non-verbal communication throughout the interview, and though we attempted to write these down as field notes, we acknowledge that longer and more systematic observational periods would have been of great assistance. Initially, we had planned to have observations as a data collection method, but due to the limitation in time and the sacredness of the delivery and newborn period, this was not possible.

I also used video recording as a method of data collection. We video recorded one of the complex phenomena that emerged in both parts of the study; the herbal mixture called *kyogero*. This is a collection of various herbs that are boiled together to create a solution with which a newborn is bathed. A part of this solution is dropped into the mouth of the baby and onto the umbilical cord of the baby for various roles as explained later on in the text. Since *kyogero* is composed of various herbs where each herb is claimed to have multiple benefits to the baby, we requested a TBA to demonstrate this process while being filmed. The TBA showed the raw herbs, the boiled solution, and the various roles of each herb; there by making it easier for the person who was not present to better understand the process. English subtitles were added to this video, and it's presented in its raw version without any alteration to the content. Despite the fact that we obtained consent to film the procedure, due to the tension between TBAs and the legal authorities in the country, I hid the face of the participant to protect the identity.

## Data handling and analysis

All the interviews were audiotaped and field notes written down during the interview process. The collected data was kept confidential. Computers storing the data were always password protected. Data was transcribed and translated in the event that the interview was conducted in a language other than English. A professional transcriber and translator did this and provided the English transcripts in word. Since I had been present during all the interviews, I would then proof read the transcripts comparing them to the audio recording. Data analysis was conducted throughout the entire study period. I used qualitative content analysis (63) to carry out the analysis. I also borrowed from a modified Giorgi analysis, which included immersion in the data, identifying meaning units, abstracting content of meaning units and summarizing the importance, during the analysis (64). The entire interview was the unit of analysis. Interviews were reread a couple of times to get familiar with their content. Words, sentences or paragraphs that relayed a similar message were grouped as meaning units, which were then condensed and labelled with a code. I aggregated similar codes to form categories. Categories were made to be mutually exclusive, whenever that was possible and to include all the information related to the content area being discussed. Categories were further analysed to form sub themes and themes from their latent meanings (63). I identified sub themes and themes by searching for repetitive concepts, metaphors and basing on content areas chosen before data collection (65). This was an iterative process where latent meanings within and between categories were constantly compared and reconciled (66). Two other independent researchers looked at the interviews, categories and subthemes generated. I used Nvivo 11.0.0 (QRS International, Cambridge, MA) to organize the analysis process. After the final analysis I attempted to locate some of the participants and discuss with them the findings of the study to get their views about it. I located two Traditional Birth Attendants and two study Nurses

for the re visit. Since I did not have the resources to track down the mothers, I conducted telephone interviews with 4 mothers.

Table 3: Examples of meaning units, codes, categories and themes from content analysis of interviews about acceptability of chlorhexidine for umbilical cord care

Meaning unit	Code	Category	Theme
She was calling me and she was	Mother's worry	Delayed cord fall	
wondering why her baby's cords	of delay	off	
usually take around 7 days, 3			
days, how come that this one is			
taking up to two weeks and it			
hadn't fallen off			
Me I perceive it in a weird	Scepticism with		Barriers to the
wayright now if I had a kid I	chlorhexidine		use of
would use the normal saline, I			chlorhexidine
wouldn't use the chlorhexidine.			(Deduced
			theme/content
			area)
The intentions of using kyogero	Holistic nature of	Exclusivity of	
are various but this drug is used	kyogero	chlorhexidine as a	
with only one intention of		barrier	
making the cord dry so that it			
does not smell			
I don't think they can leave out	Unwillingness to		
kyogero entirely	depart from		
	kyogero use		

# Researcher profiles

I am a male medical doctor, who trained in Uganda and practiced as a general practitioner for 1 year. Currently I am doing a Masters in Philosophy in international health at the University of Bergen. I completed a course in advanced qualitative methods from the University of Bergen, before I embarked on this research. I got to know about this study from my supervisors who designed the RCT. I was given the lead task of designing and implementing

the qualitative component of the RCT. I belong to a different ethnic group than the majority of participants in the area. However, having grown up in the central region, I fluently speak the local language and hence did not need an interpreter during the interviews. Since I spent my entire childhood in the central region, I could identify with the various practices. The use of traditional herbs was a common practice in my parents' household, and I personally used herbs a couple of times to treat myself. The practice of bathing herbs for good fortune is also a practice I grew up seeing both in and outside my homestead. However, after enrolling to medical school, I encountered less of these practices and had assumed that they had been replaced by modern practices. I was surprised to find that traditional herbs were still very popular and used by members from various strata in the community.

The fact that the local language was not my mother tongue, made me employ a professional translator to do the transcription that I proofread to correct any errors. My prior training and experience could easily lead me to be or sound judgmental and answering any questions in the midst of the interview could easily bias the participant. I therefore made it a point to act as neutral and as empathetic as possible and not to answer any question in the midst of the interview however tempted I was. I would simply tell them that questions would be addressed at the end of the interview. I could not hide my identity as a health worker since this was stipulated on the consent form. To avoid getting socially desirable answers, I would make it clear to the participants that my mission was to get knowledge from their experiences and understanding, in order to inform future health policy. This usually made them enthusiastic to share their viewpoints with us. However, there is a general reverence of health workers in Uganda with most people comfortable with sharing very sensitive information with them. This could actually have acted in my favour.

#### **Ethical considerations**

Ethical clearance was obtained from the research and ethics committee of Makerere University, School of Medicine (SOMREC) and the Uganda National Council of Science and Technology (UNCST). Written informed consent was obtained from every informant. A transport refund of Uganda shillings 10,000 (\$2.86) was given to the participants. This amount initially thought to be very modest, might have turned into an incentive to some participants. I experienced situations were participants expressed interest in participating in future studies if similar transport re-imbursement was given. Participants were assured of confidentiality and anonymity. This was important since some of our study participants were TBAs and could be targeted for litigation. I had to win the trust of TBAs before they could talk to us. This was done by explicitly explaining our motive as being a research endeavour and also having a gatekeeper, who was the head of TBAs. I also studied the RCT nurses and hence had to assure them of confidentiality, as they did not want their responses to confound their employment status. Direct and indirect identifiers such as age were also removed from the results. This is because the source population of the TBAs and the study nurses is very small, and someone can easily guess which participant said what just by knowing the age. One ethical dilemma I faced was studying TBAs, who are outlawed and could be potentially targeted for litigation as a result of our study. Since the village we studied accepted TBAs, this made their participation less risky. I also removed any potential identifiers from the methodology section and from the quotations, like the specific age of any participant, name of the village and the name of the health centres to reduce the possibility of tracking down these TBAs. I video recorded a TBA, after obtaining consent as part of my data collection. Despite the fact that she consented to be video recorded, I anonymised the video by blurring her face.

I also present quotes without identifiers like age because most of our study participants can be tracked with such identifiers. An example is the study nurses, who are about ten in number, adding the age of the person quoted can easily breech the confidentiality.

# **Findings**

I will present the findings of this study in two chapters. This is because the study was conducted in two parts that addressed two separate but connected issues. In Chapter 3, I present umbilical cord care and meanings attached to the umbilical cord in a community in Mukono district. Apart from two traditional birth attendants, the participants in this subgroup are entirely different from those in the second part.

Chapter 4 presents findings on perceptions and experiences related to chlorhexidine use for umbilical cord care. All participants in this group had an experience with chlorhexidine, which is a relatively new product in the studied communities. In addition to Mukono district, participants were also recruited from Kampala district. This part of the study was closely linked to the ongoing RCT.

# Chapter 3: The cord and its meaning: "The cord is the child"

The umbilical cord carried symbolic meaning that extended beyond the health of the child and the newborn period. The way it was treated and kept reflected parental care and responsibility and was important for the future wellbeing of the child. Using Mary Douglas' conception of the body boundaries and of how matters change meaning as they pass these boundaries, I will try to understand the meaning of the cord and how it changes after cutting and after fall off.

# The changing meanings of the umbilical cord

The changing meanings of the umbilical cord are illustrated in the response of one of our participants when asked what she meant by saying that: *the cord is the child*,

If a child doesn't have a cord he can't grow in the mother's womb. The cord can also be used to prevent someone from conceiving. The other lady told us that she could use her knowledge to prevent you from producing again. If you produced one boy, she then stops you from producing again. That means that she has killed many children. Don't you see that the cord is the child? She has stopped you after one child and you are not able to produce others. The other issue is that of confirmation of children. If there is no cord you can't explain that you produced a child who belongs to that clan. (TBA IDI)

### Inside the womb: 'The umbilical cord is the centre of life'

The umbilical cord was appreciated as a vital organ necessary for child growth in the uterus. It was seen as a passage of nourishment from the mother to the baby without which the baby would not survive in the mothers' womb. Citing that particular role of the umbilical cord, a TBA told us: *We see this umbilical cord as the center of life (TBA IDI)*. Further explaining, a

participant in a FGD told us: The umbilical cord is the life of the child because it's where the child breathes. If it's cut off before time, the child could die. (Grandmother FGD)

### On the surface of the baby's body: The cord as a source of tension

Our participants viewed the umbilical cord of newborns with a mixture of anxiety and fear. They were uncomfortable with the umbilical cord as it was an organ expected to be inside the mother's body and connecting mother and child. After delivery, when it was cut and was seen as a stump on the surface of the baby's body, it was a source of discomfort as it appeared to be outside, but connecting to the inside of the baby's body. This discomfort and fear was partly due to the way it looked as a mother told us: *The umbilical cord looks like meat (TBA IDI) and* others say: *Mothers fear the umbilical cord because it looks like an intestine (Health worker IDI)*. Another health worker explaining the fear stated: *They fear the cord because one; it doesn't look like the normal skin, and two; there is some little blood in the beginning, and as it shrinks it forms a certain discharge, I think that is what makes them feel it is painful. (Health worker IDI)* 

The discomfort and fear was also related to the perception that the umbilical cord was a vulnerable point of the child or a point of weakness. Through the umbilical cord, various illnesses ranging from physical illnesses to spiritual illnesses could enter the body of the child. A traditional birth attendant commenting on this said:

Take the umbilical cord to be an opening on the baby's body. If you are not so careful about it, chances of germs entering are so high. Even the cord itself attracts organisms like doodoos (small insects) because of its scent. So even if it is the germs we can't see with our naked eyes, they can easily be attracted.(TBA IDI)

The child was seen as vulnerable to these illnesses for as long as the cord was still attached to the body of the baby and a mother illustrated by saying: *Before a child's umbilical cord is* 

closed, I don't count it as my child because the child could die any time (FGD young mothers). Examples of such illnesses included tetanus and Etumbizi, a local disease category. Etumbizi was described as a disease caused by air entering the newborn, resulting in foaming around the mouth and subsequently death. Etumbizi could also result from negligence in covering the baby well. Describing Etumbizi, young mothers in an FGD told us: That air can enter through the umbilical cord and affect the baby if you don't cover him very well. (FGD young mothers)

Once the air had entered the child, one TBA told us:

In case the air enters, it can affect the baby. For example if you leave a polythene bag somewhere and air enters in it, this polythene bag swells. And if air enters the baby, the stomach swells. And because our body has many organs, the lungs are affected. Many body parts are affected but mostly the lungs. So if air enters the lungs it is dangerous to the baby. That is why they get persistent cough. And that is why you see that the baby should be covered straight away so that he doesn't inhale a lot of air. (TBA IDI)

In *Etumbizi*, it was not only the cord that could cause air. The air was also thought to enter from other places like the mouth while breastfeeding, but for this there were simple remedies. Another disease the newborn was vulnerable to if they still had the umbilical cord was *Busobe*, another local disease category. *Busobe* was described as a disease caused by an adulterous father coming in contact with the newborn. This was perceived as a very serious illness, with very few known effective cures and in most cases lead to death. One traditional birth attendant described a case to us:

The father needs to be faithful to the baby's mother and if you the father came from your other woman and touched this baby, he will become sick of busobe disease and even die. I saw it happen. Mrs. K's child almost died. The man came from somewhere

and touched the baby then he started convulsing, the skin started turning yellow and he started producing foam from the mouth. (TBA IDI)

There was also an appreciation of some biomedical diseases that could affect the newborn through the umbilical cord; the most commonly cited being tetanus. Other diseases were also mentioned as reported by a TBA:

Sometimes if the mother is HIV positive and they don't tie the umbilical cord very fast then the baby can get infected with HIV from the mother. If the mother has syphilis the baby can get syphilis (TBA IDI)

As a result, there was a desire to have the umbilical cord detach as fast as possible to reduce this period of anxiety and uncertainty as a health worker informed us:

The cord is a delicate part on a baby and when it is still there, it gives you tension. So it has to go off so that someone can be free. Remember you have to be there to care for it, and this puts the mother in tension. (IDI HW)

### After detachment: "The cord is the passport to the clan"

After the umbilical cord falls off the newborn, it was looked at in a completely new way. The umbilical cord was generally seen as a treasure, something that is of so much value and kept very safely as a TBA told us:

There is even a saying that protect your child like you would protect the umbilical cord, the saying applies to anything, for example your phone, they say protect your phone like you would protect the umbilical cord, they say this because the cord has the importance of proving that the child born belongs to this clan. (TBA IDI)

The umbilical cord was seen as a treasure because it was used in a traditional practice known as *kwalula* to prove that the child truly belongs to the father and hence belongs to the paternal clan.



Figure 4: Umbilical cord remnants of 7 children kept for over 20 years

This ceremony had no strict timetable but all women were required to be ready because they could be summoned at any time. Because of this need, most women had to store the umbilical cord remnants very safe away from predators like rats or relatives who may not wish them a happy marriage. In case the umbilical cord remnant was misplaced, this could be a source of worry as a mother who had lost the umbilical remnant of her child stated: *I am worried, I keep searching for it all the time, because if someone picks it, he can do something bad to my child.* (Mother IDI)

The *kwalula* ceremony was usually performed at the husbands' cultural home and would either lead to jubilations if the paternity test was positive or a rebuke and demand to return the

child to the true father if it turned out negative. One participant explained the *kwalula* ceremony:

They get a basket and put water in it, they smear ghee on the cord and then they put it in the basket containing water. If the cord sinks to the bottom of the basket then we rejoice and say that it is our child but if it comes to the top then we say the child is not ours Even if you give birth to twenty children, you have to keep the cords from the first child to the last. In fact, places where women keep these cords are not easily accessed. We would give our lives fighting to secure that place. We do take care of you until you grow but later we need to confirm, are you our child. (TBA IDI)

The *kwalula* ceremony was seen as an alternative to modern day DNA testing. The older mothers preferred *kwalula* to DNA testing, as they perceived it as cheap, genuine and impossible to bribe, while the younger mothers preferred the convenience offered by the current DNA testing. A mother in a FGD for older women stated:

And if we are to go back to the native way of confirming children, instead of wasting millions of money paying for modern DNA tests, this cord helps a lot in that aspect. If you get misunderstandings with your husband just tell him to prepare and you go to the village for kwalula (FGD Older women)

However, the umbilical cord remnant though treasured was not supposed to come into contact with the genitals of a male child as was well elaborated by one of our participants:

The moment a woman leaves the cord to fall on the baby's penis, have you heard of impotent people? Sometimes they say that they were bewitched but it is not witchcraft.

It is because the mother was careless and the cord fell on the baby's penis (TBA IDI)

To prevent this unfortunate scenario, a grandmother told us: You have to cover him with a cloth or short if the cord is almost falling off so that it does not fall on his penis (Grandmother FGD)

A TBA told us of other dangers of the umbilical cord remnant:

What they told me is that men can use it to prevent their wives from conceiving with other men. You know she can decide to leave you when you still love her then you also tell her okay you will not be able to get babies from there. Things like that but that is high level science and I don't know much about it. But men actually do it and any other person who is not your husband can do it in case he takes the cord away from you. (TBA IDI)

A mother also commenting on a similar concept stated: That cord does not affect only the child but it also affects the mother. For the mother someone can perform witchcraft on it and you fail to conceive again. (Mother IDI)

## Cutting and healing of the umbilical cord

There was an awareness of the importance of hygiene and cleanliness when cutting the umbilical cord. Mothers who delivered from health centres reported the use of brand new razor blades or surgical blades, usually part of delivery kits, during the cutting of their baby's umbilical cord. For the deliveries that were conducted by the TBAs, effort was also made to ensure that the substances used to cut the umbilical cord were sterile as one TBA informed us:

Ever since we started we have been using razor blades but if you are to use a razor blade, we usually have new razor blades, you get it when it is new. Now we mostly use scissors. But you also boil them; we do not use them before sterilizing. We do have stoves and local fireplaces for the sterilization process. You use usual water put the scissor in a pan, cover then boil like you boil something to eat then remove it and put on a clean plate to cool off so that it doesn't burn you when you are using it. We do this to prevent germs from infecting the baby. (TBA IDI)

In the past, substances like elephant grass and bamboo were used to cut the umbilical cord but this was now seen as an old tradition that was no longer practiced in this society as a TBA informed us: *They would get a bamboo stick and use it to cut the umbilical cord. But now in our era we are using razor blades. (TBA IDI)* 

After cutting the umbilical cord, a number of materials were used to tie the umbilical cord with most mothers who delivered from the health centres reporting the use of pieces of gloves or pieces of thread. Traditional birth attendants mostly reported the use of threads when tying the umbilical cord.

A number of substances were put on the umbilical cord and this was mainly done to increase its drying and eventually to hasten its fall off as a mother explained:

The issue of not putting anything on the umbilical cord, it's like when you have a wound. A wound without treatment takes long to get cured but a wound on which you have applied medicine gets cured very fast. So if you have medicine that you apply, the cord goes off very fast. (Mother IDI)

These substances included: a herbal mixture locally known as *kyogero*, surgical spirit, powder, banana (plantain) powder, ash, soap, normal saline, tealeaves, ghee, *kiyondo (a local herb), dung (lizard and cow)*. As regards the motive behind applying most of these substances, a TBA told us:

The intention was to make the umbilical cord dry because even after the cord had been removed they would continue putting powder on the spot where the cord has been cut so that it dries up. (TBA IDI)

There was also an awareness of the bio medical role of some substances applied on the umbilical cord in prevention of infections as a TBA told us:

We do get surgical spirit from the hospital then you get cotton dip it in the spirit, then clean the umbilical cord. I think it is also to prevent it from rotting, smelling and to make it dry (TBA IDI)

Substances were also applied after the umbilical cord fell off to ensure that the gap left would seal off as first as possible:

They would get a piece of gonja (plantain), roast it and then they would grate it and then get powder out of it. Then they would pour the powder where the cord broke off so that the umbilical cord would dry up and get cured very fast. (TBA IDI)

Umbilical cord care was thought to begin during pregnancy with some foods thought to prolong umbilical cord fall off time, for example, the practice of eating the intestines of cows (a local delicacy) during pregnancy. These habits were consequently avoided.

The role of men in childcare was summarised by a TBA below:

Care for new born babies starts with the man, if you have cared for the lady properly then she can care for the baby as well. But if care for the lady is bad consequently care for the baby will be poor. It starts with the man. If the man bought enough cloths then the woman will care for the baby very well. But if the man doesn't care then care for the baby has to be bad. (TBA IDI)

Newborn care also included secluding of the newborn and limiting access to the newborn until the umbilical cord fell off. This was done to protect the newborn from various dangers, in the period of maximum risk. Commenting on this a traditional birth attendant told us:

When I was growing up, my grandparent told us that the baby is not taken out of the house before the cord has broken off and you should not cross-junctions with the baby. They also used to tell us not to give the baby to people because you don't know where they are coming from and don't know what they have been doing. The person could be coming from doing wrong things then they come and you give them your baby. Have you heard of busobe disease? You will give him bad omen. So they leave the baby for the mother and a few people who care for him. (TBA IDI)

# "Without kyogero there is no blessing"

The word *kyogero* comes from the stem *-kwoga* meaning 'to bathe'. The name *kyogero* literally means what should be bathed in.



Figure 5: Kyogero in the raw form (left) and the cooked form in a sauce pan (right)

*Kyogero* is a combination of a number of herbs each with a different role as illustrated in the attached film. These herbs are boiled for 6-8 hours in a brand new saucepan. After the *kyogero* is ready, a few drops are dropped into the baby's mouth and onto the umbilical cord

and there after, the baby is bathed in the *kyogero*. The leaves and barks are used as a sponge and the water is used sparingly. It's during the bathing that the baby's umbilical cord indirectly gets in contact with *kyogero*. After the baby is bathed, the remaining *kyogero* is kept for approximately a week. Before re-use, the *kyogero* is reheated to a temperature deemed fit for the newborn. The *kyogero* is usually kept for a week because it's very cumbersome and expensive to prepare. When applied to the umbilical cord, *kyogero* was believed to hasten umbilical cord fall off as a mother reported:

Now like me it is the kyogero that facilitated the breaking of the cord. I did not apply anything else because I hear people saying that other things are dangerous to the umbilical cord. (Mother IDI)

However it was the extra roles of *kyogero* that made it very popular among the participants. as a TBA told us:

We do use ebombo to bath a child then we also put in another herb called lweza (components of kyogero) We use these because they are the authors/owners of blessings (TBA IDI)

These blessings could manifest later in life as in various ways as one participant clearly stated:

Now for example a girl getting married to a rich man who also has good manners.

Have you ever sat down and said so and so's children are all married to rich men or they all have jobs. So that is one of the benefits of the kyogero according to our grandparents (TBA IDI)

*Kyogero* was also thought to smoothen the baby's skin and clears a common newborn rash locally called 'noga'. *Kyogero* also guarantees peace for the child and makes the child grow up into a calm person:

Those are the children you find so calm because they were bathed in that kyogero such a child is obedient (TBA IDI)

*Kyogero* was also perceived to immunize the child against common newborn diseases as a TBA told us:

I think that is why people in the past were not so enthusiastic with immunization because the herbs that were mixed in the kyogero prevent many diseases. Measles can attack the whole village but that baby survives because of those herbs (TBA IDI) Kyogero was also believed to make a child grow up into an intelligent person as one participant stated:

So that the baby grows with a bright mind, there is [in kyogero] what we call "olumanyo" sometimes you mix it in the tea and he drinks so that he grows up with a bright mind (TBA IDI)

It is these multiple benefits and many more that make *kyogero* a very popular herbal formulation and a major factor in umbilical cord care. The head of the maternity ward where we conducted our study said that *kyogero* use was not only common among the health seekers but also among the health workers:

They believe in it so much including the midwives who are trained. So they feel those are drugs. They call them herbal medicines, which help the baby to get a clear skin like I said good luck and all those sorts of things. (Health worker IDI)

In the situations where the baby was not bathed in *kyogero*, the baby is believed to turn out unruly and disrespectful. The child is also believed to generally be devoid of good luck. One participant told us of the possible consequences:

You also find he doesn't have blessings. Those are the children you find in Kampilingisa (juvenile detention facilities) because they are stealing phones, bathing sponges, and other things. So you see the child is not stable. (TBA IDI)

# Colic, bad smell and conflicting instructions in umbilical cord care

A number of substances were applied onto the umbilical cord to reduce colic. This was especially done after the umbilical cord had fallen off. A mother explaining some of the substances applied said:

Most people use the kiyondo after the cord has fallen off because after the cord falls off, it leaves something like a wound. So our elders say that the "kiyondo" prevents the baby from abdominal colic and over crying. The baby can cry for the whole night. Some parents say that you can use ash from matchsticks by putting it on the umbilical cord to help it dry very fast. (Mother IDI)

Other substances applied on the umbilical cord included tomato extract, saliva and mushroom *(obutiko obubaala)* as a mother explained to us:

After the cord had fallen off they told me to put mushrooms. They said that they put the mushrooms in a banana leaf then steam it, after bathing the baby you squeeze water out of the mushrooms then put drops on the umbilical cord. (Mother IDI)

One of the major challenges with umbilical cord care was the foul smell associated with the umbilical cord of newborns as one mother told us:

The more it stays the more it smells. So if you don't keep it clean it smells a lot and even attracts houseflies. Some women produce babies and don't take care of the umbilical cord as they clean the baby. Flies can even fall on the baby, this we have ever seen. (TBA IDI)

### Another mother told us:

That umbilical cord smells so the baby should not be taken out of the house before it breaks off because it can attract flies. (Mother IDI)

Another challenge associated with umbilical cord care was the confusion with the instructions that were given by the health workers concerning the various substances used in umbilical cord care. Concerning the use of salt water, one TBA told us:

One tells you use, the other tells you don't use. And we at the grass root our minds get confused because we have that and we would have liked to use something different.

But if this one comes and tells you to use then another tells you to not use, you get confused. (TBA IDI)

Some health workers also recommended dry umbilical cord care, which is what the current guidelines state. Dry umbilical cord care necessitates that the mother doesn't put anything on the umbilical cord including salt water.

The recommendation to practice dry umbilical cord care was seen as a challenge, both to the mothers and the health care workers. To the mothers, dry umbilical cord care was thought to delay umbilical cord fall off and hence a source of prolonged anxiety. When we asked a traditional birth attendant the challenges of dry umbilical cord care, she replied:

You know our bodies behave differently. There are those who easily get infections and those who don't. So by not putting anything you have not helped (those who easily get infections) also the way people care for the umbilical cord is different. So now you see this medicine of yours, it helps a lot. When you put, it dries very fast within two to three days (TBA IDI)

A mother explaining why she disagreed with dry umbilical cord care stated:

The issue of not putting anything on the umbilical cord, it's like when you have a wound. A wound without treatment takes long to get cured but a wound on which you have applied medicine gets cured very fast. So if you have medicine that you apply, the cord goes off very fast. (Mother IDI)

## Responsibility in umbilical cord care

The responsibility of umbilical cord care was usually shared between the mother and older female caretakers in cases where there were older female care takers. For younger mothers, the older female caretakers usually took the sole responsibility for umbilical cord care in the immediate period after birth when the mother was perceived to be very tired. Older female representatives were perceived to be more experienced and their suggestions of umbilical cord care were usually adopted as a health worker informed us:

They believe in them so much because they stay with them 24 hours. They come here to the hospital for a short time and then they go back. We haven't built that strong relationship with them to believe in us. Most of them believe that their grandparents know more than what we know because they have gone through it and they have been caring for them and their grandchildren actually they beat us using experience and age. (Health worker IDI)

This usually influenced whether or not mothers followed the recommended practices as a health worker told us: Sometimes the mother comes back and tells you that you told me to do ABCD but my care taker was the one bathing the baby so she applied this. (Health worker IDI)

In cases where the younger mothers lacked older female relatives, they would usually turn to neighbours who had ever given birth for advice. Older mothers usually began taking care of their children early on and they were usually more confident as they had often taken care of the umbilical cord a couple of times before. A health worker commenting on the first time mothers stated:

Especially the prime gravidas, who have no idea at all on what to do, those having the baby for the first time, they have many ideas from different corners. They listen to all ideas from different places. (Health worker IDI)

# Chapter 4: "We shall count it as a part of kyogero"

In the analysis, we identified factors that seemed to facilitate chlorhexidine use and other factors that seemed to hinder adherence to the exclusive use of chlorhexidine for umbilical cord care.

### **Facilitators to the use of chlorhexidine**

#### Convenience

Participants considered chlorhexidine use for the umbilical cord as very convenient. Chlorhexidine was thought to be convenient because it was found at the facility and distributed at the time the mother needed it. The alternatives like the herb *kiyondo* needed technical assistance to identify, and were not readily available in urban areas where most of our participants lived. Prior to chlorhexidine introduction, mothers' had to rely on older caretakers like grandmothers and aunties, to suggest or bring the necessary substances, which ranged from plantain ash to complicated herbal formulations, which most mothers didn't know. One participant commented: *Those that I tell about this drug see it as a good thing because some of them find it hard to get transport fares to go and consult their grandparents*. (Mother IDI)

Participants also felt that the single dosage of the chlorhexidine was of so convenient, as they did not have to remember dosage timings, which they often forgot. The care providers also expressed a difficulty remembering dosages. This is very important for traditional birth attendants, who have to follow up their clients at home and hence would have the responsibility of administering the chlorhexidine as one TBA said:

What makes life difficult for me even if it is medicine is telling me to use 2 tablets three times. I might swallow in the morning then fail to swallow the second time because I am away from home as a person with responsibilities (TBA IDI)

The convenience was also brought about by the way the chlorhexidine intervention was administered. The study nurses were the ones applying the chlorhexidine. Most mothers expressed a fear of the umbilical cord, as mentioned in part one of the study, rather, having a health professional do this daunting task would be very convenient. A mother talked about that when asked who she preferred to apply the chlorhexidine:

I think it would be better if the medical personnel did it because some mothers even fear touching the cord they say "me I don't want to touch that" but for medical personnel they know what to do. (Mother IDI)

Chlorhexidine was also convenient for some younger members who viewed herbs as old fashioned and backward. Such perceptions are not very prevalent but they increase by the day:

They don't like using plantain because it is seen as being backward unless if it is us (the older relatives) who apply it but that is sometimes impossible as some husbands limit their wife's movement. (TBA IDI)

Health workers also perceived chlorhexidine to be convenient compared to the salty water they had previously been using. A health worker told us:

Chlorhexidine is not time consuming but now with the salty water you have to first boil the water, then you measure the salt, then sterilize the cotton you are going to use, that is really time consuming but when you use chlorhexidine you don't need to advise the mother to do this do this. (Health worker IDI)

As a result of the packaging of the chlorhexidine, application of the medication was thought to be very easy. When asked about how easy it was to use chlorhexidine, a traditional birth attendant told us:

It is very easy. You just open the bottle and then apply it. Since the chlorhexidine is packed very well then I think even the mothers can apply it. There is no problem with that. It is not like an ointment where you have to collect some and then smear on the baby. The chlorhexidine is packed very well and there is no direct contact with fingers. Even if someone is not so clean, they can apply it. (TBA IDI)

However, other health workers advised against giving the drug to the mother to apply it themselves. They reasoned that despite the ease in application, mothers' fear of the umbilical cord would affect the application success.

### Reducing bad smell and colic

Participants perceived chlorhexidine to be better at dealing with certain issues compared to the alternatives they were previously using. The smell of the cord was one of the issues they perceived chlorhexidine to be better at dealing with compared to alternatives. Mothers reported that the umbilical cord usually produced a foul smell both when on the baby and off the baby. Mothers disliked this foul smell because it gave an impression to the visitors that the mother was unhygienic. The smell also hindered visitors from holding the baby. Some mothers also attributed the hesitancy of their husbands to hold the newborn to the foul smelling umbilical cord. When the umbilical cord was off the baby, the smell attracted rats to the cord remnant and sometimes the rats made off with this 'treasure'. Anything that could prevent the umbilical cord from smelling was very welcome. Chlorhexidine seemed to do just that and hence appreciated by most mothers. One mother said:

Another reason why people like it is because it prevents the cord from smelling. My mother in law asked me whether the cord smelt, whenever she called on phone she would ask me whether the cord smelled and I would tell her that it did not smell. She would even call her son and daughter to confirm. She wanted to apply the local medicine because I had told her that the doctor refused us to put anything else but she doubted and she would ask her daughter and son because she did not trust me. They would also tell her that it did not smell. So if someone gets to know that it prevents the cord from smelling, she can use it because no one wants to stay with a smelly umbilical cord. (Mothers FGD).

The smell from the umbilical cord is not limited to the baby as a mother told us: "You can enter a house when it has a bad scent but for this one, the cord did not smell." (Mothers FGD)

The umbilical cord smell could also predispose the child to harms and dangers as a grandmother told us:

Now what I realized is that this drug is better than our herbal medicine. The cord does not smell even though it lasts for seven days. With our herbal medicine the cord lasts for four days but the cord smells a lot and even when you move with the baby, that cord smells a lot. There is a friend of mine whose child was killed by the rat because it ate the cord. If you have rats and you are not clean that foul smell attracts the rats and they can bite the umbilical cord. (Grandmother IDI)

In addition to the reduced smell, participants felt that the cord dried up faster and looked less slimy as one health worker noted: When you put it on the baby's cord, you see the changes there and then because you see the thing (umbilical cord) begins to shrink. (Health worker IDI) This quickened drying was beneficial as it encouraged some husbands to participate in newborn care early on as a mother told us: When I told him that the cord had dried up he was surprised, he asked whether he was not going to harm the baby and I told him that there was

no problem, so he carried him because he was also seeing that it was already dry. But before he would say that "I am going to harm the baby". (FGD Mothers)

Another perceived benefit to the use of chlorhexidine was the reduction in abdominal colic. Most mothers expressed a challenge in dealing with abdominal colic, which prompted them to apply so many herbal formulations to the umbilical cord in an attempt to prevent umbilical colic. Abdominal colic was hence a major reason for applying herbal formulations onto the umbilical cord both before and after umbilical cord fall off. Most mothers were often disappointed, as most recommended potions did not help. A number of mothers who had nursed a baby before noted that the baby on whom chlorhexidine was applied did not experience abdominal colic. This notion was expressed both in the individual interviews and in the focus group discussions, however they did not have any explanations for this observation. A mother told us: *compared to the previous baby, this child did not complain of abdominal colic. (Mother IDI)* 

### Chlorhexidine is a pleasant liquid

All the participants reported they liked the colour, smell and formulation of the chlorhexidine used in the study. They were very happy with the evaporating nature of the drug on the skin, leaving no trace of prior drug application and hence not staining the umbilical cord or the clothes of the baby. They compared this with vaseline like ointments which were perceived to attract dust and hence infections. One participant said:

I liked this liquid formulation. If it is an ointment, dust easily sticks to it. You know if it is in an ointment form and dust blows over the cord, the dust can stick on the cord, which is not the case with this liquid form. The ointment absorbs anything very first and that way we can't avoid infections. (Mother IDI)

However some reported that the cold liquid irritated the baby, and this sometimes caused crying. However none of the participants reported future rejection of chlorhexidine due to this irritation. When asked to elaborate the irritation a mother told us: *It was cold in fact the baby shivered a bit. (Mother IDI)* 

#### Difficulties in obtaining local formulations

Mothers reported challenges in obtaining the preferred herbal formulations for use in the care of the newborn. Most of the young mothers we interviewed did not know the details of the herbal formulations and had to rely on older relatives to get them.

This often led to a delay and sometimes inability to use them as a mother said:

I didn't use the kyogero because I didn't have access. Most times in the city there are no old people like your mother or aunt. (Mother IDI)

With urbanisation, it was also increasingly difficult to obtain these herbs due to the cutting down of forests.

### Willingness to defer kyogero to after fall off of the cord

The exact time of when to start bathing the baby in *kyogero* was not clearly set for most of the participants. Whereas the most experienced older participants insisted that the bathing should commence on the first day, there was an appreciation of the delays in obtaining *kyogero* and hence starting its use later was also accepted. The younger mothers usually initiated the bathing after the first week, usually when the umbilical cord had detached. When participants were questioned whether they could delay bathing the child in *kyogero* until the umbilical cord had fallen off, most of them replied affirmatively as a grandmother reported below:

We did not bath the baby with kyogero before the cord had fallen off because they (health workers) refused us (to do it). We bathed him with kyogero after the cord had fallen off. What the doctors have to tell the people is that they should wait for the cord to fall off then start using kyogero on the babies because it is not so late by that time. That is what we did. The cord first fell off then we started using kyogero the following day and nothing happened. (Grandmother IDI)

However this does not mean that they would not put anything after the umbilical cord had fallen off, substances put during this time had other purposes, usually the prevention of abdominal colic. Telling mothers to abandon their practices would be equivalent to chasing them from hospital as a mother who had earlier on reported bathing her child with *kyogero* commented as regards discouraging mothers from using *kyogero*:

For example with Baganda, if you tell them to abandon kyogero then you have blocked the baby's blessings. Yes you have chased her away from the hospital because you want to abolish culture. So you don't tell her to abandon kyogero. Tell her to use it when she gets it but during the first seven days, tell her to get herbal soap and vaseline to bath the baby as the cord also breaks off. When the cord breaks off, she is free to use kyogero as often as she wants. But if you refuse them especially the Baganda, they will say that you are abolishing culture because a baby cannot stay without kyogero. (Grandmother IDI)

### Barriers to the use of chlorhexidine

### Delayed cord fall off

Outside of the study, by the mere experience of it prolonging the cords falling off, I wouldn't really go for it. (Health worker IDI)

Mothers of babies in this area expressed unease with the umbilical cord of newborns. They feared the umbilical cord and perceived it to be very vulnerable. Therefore, most mothers desired the umbilical cord to fall off as fast as possible. Contrary to their desire, most participants reported delayed cord fall off. Most mothers however did not attribute the delay to chlorhexidine as explained by one traditional birth attendant:

The baby's mother told me that the cord might take long to fall off because the mother ate a lot of cow's hooves (mulokoni) while pregnant. They say that when you eat a lot of cow's hoof, the cord takes long to dry up. It might be true because I personally experienced it with one of my pregnancies. There is one pregnancy where I ate a lot of cow's hooves and the cord took long to dry up and even cover up. (TBA IDI)

Unlike the mothers, most health workers were convinced that the delayed cord fall off was caused by chlorhexidine. Most of them were comparing the children from both arms and were noticing a longer period of cord fall off in addition to receiving similar complaints. One health worker told us:

Most of the mothers that we applied chlorhexidine, there is delay in falling off. Up to two weeks. On Friday I had a mother, she was calling me and she was wondering why her earlier baby's cords usually take around 3-7 days but this one is taking now coming to two weeks. (Health worker IDI)

Some health workers further reported that having experienced quicker cord fall off with other alternatives like saline water, they were unlikely to adopt chlorhexidine after the study:

If I am to compare these mothers with those who we didn't give chlorhexidine, it's like their cords delay to fall off. I perceive it in a weird way. If I had a child I would use the normal saline, I wouldn't use the chlorhexidine. (Health worker IDI)

As a result of delayed cord fall off, some level of scepticism was also expressed by mothers towards the drug, and some mothers reported reverting to herbal formulations, which are

thought to speed up the cord fall off. This becomes a barrier to exclusive chlorhexidine application, which is the desired practice. One health worker reporting her conversation with one such mother said:

There is one mother. She came when the cord wasn't falling off then she asked and we told her it was still not very dry and would fall off. She then told us that the mother in law told her that "don't you think that foreign medicine that you are using has undesirable effects?" then she told her to use salty water or kyogero so that it can fall off very fast. For us with our kids we were not putting those things and they were falling off very fast, how come with your kids it is taking so long. So I couldn't stop her. (Health worker IDI)

Another mother reporting her experience with delayed umbilical cord fall off said:

I was with my mother in-law when the doctor was telling us not to apply anything else, but when she was bathing him the following day, she said that let's put something so that the cord could fall off quickly. (FGD mothers)

This delayed cord fall off could hinder the scale up of chlorhexidine as very few mothers would attempt to try out a product, which is rumoured to delay cord fall off. Health worker scepticism would further discourage chlorhexidine use as health worker doubts are treated with special attention. However, some mothers stated that had they been fore warned, they wouldn't have been as alarmed as they were. Health workers also shared that view as one told us:

I think when we talk to them, we educate them on the benefits of chlorhexidine, the chances of cord infection are low even if it takes long to get off but the cord is safe than putting these other things which will speed up the falling off of the cord and then the baby ends up with an infection. I think with proper health education and

sensitization the mother can be patient since it doesn't take a whole month she can be patient for two weeks. (Health worker IDI)

Delayed umbilical cord fall also affected the day to day lives of working mothers as a traditional birth attendant told us:

If it delays then we shall go back to the traditional methods because today people no longer have time. You find one wishing for the cord to fall off very fast so that she can carry the baby on her back and then do her work. I wish this cord cures very fast so that I leave the baby with the maid. Because if the baby cries a lot before the umbilical cord cures, it can enlarge so most women wait for the umbilical cord to cure very well so that they can do their own other work. (TBA IDI)

As a result of this a lot of care and nurturing was provided when the umbilical cord was still intact as a mother informed us during a focus group discussion:

When the baby cries before the cord has fallen off, the umbilical cord is affected. That is why you have to carry him so that he doesn't cry when the cord is still on. (Mothers' FGD)

Mothers suggested that one solution to the delay could be educating them before hand, probably during the antenatal period. The challenge to this is that many people are involved in decision-making and care for newborns, many of who are difficult to reach during the antenatal period.

## Mothers' lack of power in deciding on cord care

Decision-making concerning care of the newborn is usually made collectively with most attention paid to the older female relatives, since they have the most experience in the field. These older relatives could be grandmothers, mothers-in-law, aunties or any other women in the neighbourhood who have delivered before. This is specifically true for young mothers as

one 19 year old mother told us: Since it was my first born, my mother in-law knew everything and she was the one who bathed him because we did not know how to do it. She would ask for some salt and cotton and you could not refuse her to apply it. (Mother IDI)

To further explain this lack of power, a number of younger mothers reported delegating tasks like bathing the newborn to these older relatives who may not have been present during the health education. When asked about cord care, one young mother told us:

I did not see it properly because it wasn't me who was bathing the baby. At that time, I was afraid of him because he was so small. It was my sister called Sheila. My duty was to put the kiyondo (a local herb) on fire, and then she was the one who would put it on the cord because she told me; 'you have never given birth (Mother IDI)

This created a challenge of adherence to exclusive chlorhexidine umbilical cord care, as the care of newborns was often delegated to persons other than the mother. This meant that the person who ended up doing the actual umbilical cord care may not have received the necessary education and could rely on their previous experience. Most of these older female relatives had used various herbal formulations like *kyogero*, and they had very high regard for them. A health care worker, who had also previously had a baby, also reported of pressure from older relatives as regards umbilical cord care: *they are influenced by other people take for instance I am a daughter, I have my mother behind who is telling me to use herbal medicine. Put the baby in kyogero, I would have taken the idea but I have some one who is putting me on pressure.* (Health worker IDI)

Some mothers who were at the hospital had to first inform their husbands before decisions concerning umbilical cord care were made as a mother told us:

When they explained to me I told the doctor that I was not going to decide on my own.

Let me call the child's father and if he accepts then it will be okay. So the doctor explained to the father and he said it was okay. (Mothers FGD)

#### Resistance to using Chlorhexidine exclusively

Despite the willingness to abandon some of the substances previously used for umbilical cord care, participant were unwilling to abandon some of the other cultural herbal remedies. One of the practices participants were unwilling to abandon was the bathing the newborn in the local herbal solution *kyogero*, in order to use chlorhexidine exclusively. Chlorhexidine was viewed as an addition rather than a substitute for these cultural practices. We were told of several instances where chlorhexidine was combined with other, already existing practices as a TBA informed us:

Now just because we applied the chlorhexidine yesterday, it does not stop you from using the kiyondo (a herb applied to the umbilical cord) today if you want it. But these can't fail to work together because what I realized about this drug is that after applying it today for the first time, when you use kiyondo the next day, the chlorhexidine does not wear off the cord. Why I am saying this is because after applying it you can bath the baby tomorrow and the drug remains on the cord. (TBA IDI)

The reason these other cultural practices persisted was because they were viewed to give benefits that chlorhexidine did not give. Concerning *kyogero* one informant summarized why it is difficult for them to abandon the *kyogero*:

The intentions of using kyogero are various but this drug is used with only one intention of making the cord dry so that it does not smell, isn't that the reason? It is only on the cord, the legs are not catered for, and the head is not touched. So we can't abolish the kyogero. (Mother IDI)

A traditional birth attendant stated that since chlorhexidine was only addressing one of the many issues that need to be dealt with, chlorhexidine should in fact be added to "kyogero":

According to me the way I understood it, the essence of introducing this drug is to hasten the drying up of the cord but not these other things. We still want our blessings, we want our peace, we want everything, we want the baby's health and all this is in the kyogero. We prevent malaria; we do prevent many diseases through the "kyogero" So they will be able to work together. So you are like someone who has added on to the benefits found in the "kyogero". We shall count it as a part of kyogero. We shall call it value added kyogero. (TBA IDI)

One mother explaining why she used kyogero despite having been told not to add anything on the cord, she stated it was her mother who bathed the baby and this was done due to a number of added benefits as she states below:

I delivered on a Thursday and started bathing the baby with kyogero on a Saturday. It was my mother who bathed the baby using kyogero. It was to clean the skin, prevent rashes and keep the baby clean so that the skin doesn't peal off. They also told me that it contains blessings. (Mother IDI)

Despite the fact that mothers reported using substances on the cord alongside chlorhexidine the some times commenced this process after the cord had fallen off as a mother told us:

But I first observe this drug and know what happens after the cord has fallen off then I start with kyogero knowing that the cord fell off on its own and the kyogero also performs its own functions. (Mother IDI)

A health worker commenting on the co-existence of chlorhexidine with these cultural practices stated:

I don't think they can leave out kyogero entirely because babies get, what is that rash, like the heat rash and for them they believe that the more you put the baby in kyogero, it will go off. I don't think they will stop using. (Health worker IDI)

In summary, the findings suggest that chlorhexidine used for the umbilical cord is generally accepted but there are cultural practices like ritual washing of the new born and preferences like the quick detachment of the umbilical cord, which may hinder exclusive use of chlorhexidine for umbilical cord care. A grandmother who was helping her daughters to take care of newborns summarised it as follows: *You will store the medicine and then we shall go back home and also continue using the traditional medicine.* (Grandmother IDI)

# **Chapter 5: Discussion**

I will discuss the findings under two headings. The first heading is the meanings and care of umbilical cord where I discuss the symbolism and roles of the umbilical cord. This will draw upon findings in the first part of this study, presented in chapter three. The second heading is chlorhexidine acceptability, where I discuss the facilitators and barriers to chlorhexidine use. I draw upon findings in the second part of the study, presented in chapter four.

In the final section of the chapter, I will discuss the trustworthiness of the findings.

# Meanings and care of the umbilical cord

As shown in the findings section, the umbilical cord took up different meanings as it transitioned from inside the body to off the child's body. Inside the body, the cord was seen as a very vital organ necessary for the nutrition of the child, this was also reported in a similar study in Zambia (28). However after delivery when the cord was cut and tied and it lingered on the surface of the newborn body, the umbilical cord became a source of fear, dread and uncertainty. This change of perception was partly due to the way the umbilical cord physically appeared, with some participants stating that it 'looked like an intestine' an organ expected in the interior of the body. The fear and anxiety of the umbilical cord can also be explained according to Mary Douglas' boundary perspectives. Mary Douglas states that substances which defy boundaries, or threaten the proper separation offered by boundaries are treated as dangerous (49) due to their ambiguity, and one way of dealing with this, is the separation of such substances from the body (49). When the umbilical cord is on the surface of the body, it breaks the boundary that should be offered by the skin, by serving as an alternative connection between the outside and the inside of the body and this could explain the anxiety.

The newborn with an umbilical cord on its surface was seen as very vulnerable to both physical and spiritual attacks a finding also reported by other authors (30, 31).

This discomfort and unease with the exteriorized umbilical cord could explain many umbilical cord care practices. Underlying most umbilical practices was the desire to have the umbilical cord fall off as fast as possible, in order to reduce the period of anxiety but also to ensure wholeness of the body through the closure of the umbilical cord. The desire of mothers to have the umbilical cord fall off quickly has been reported in a couple of studies from Uganda, Zambia and Ethiopia (24, 25, 27, 28, 43). The umbilical cord also produced secretions which mothers were uncomfortable with. Powdered substances like plantain ash, normal ash, lizard excreta, and baby powder are perceived to increase the rate of drying of the jelly like umbilical cord. Other liquid substances like the herbs mixtures *kyogero* and *kiyondo* and surgical spirit are also perceived to quicken the umbilical cord drying and fall off. The concept of applying substances on the umbilical cord to quicken its fall off has also been reported in studies from other African settings (27, 28, 43, 67). When we asked some participants the single most important characteristic of a substance designed for umbilical cord care, most of them stated that the substance should quicken umbilical cord fall off.

To further illustrate how desire for umbilical cord fall off influences cord care practices, unfamiliar persons and extended family were discouraged from carrying newborns until the umbilical cord fell off, a way of protecting the newborn from ailments. Nalwadda and colleagues (32) found similar concepts in Eastern Uganda children ceased to be called newborns as soon as the umbilical cord fell off. The issue of umbilical cord fall off is therefore very important when discussing umbilical cord care with mothers' of newborns. In

addition, interventions like chlorhexidine umbilical cord care, which have been shown to increase the time to umbilical cord fall off (45, 68) may face challenges during scale up (28).

The meaning and perception of the umbilical cord changed when the umbilical cord had detached from the baby. In the detached form, the umbilical cord took on a mixed identity. The umbilical cord was generally highly regarded, as it was perceived as a treasure but this was for as long as it did not touch the genitalia of the male child, where it was thought to potentially cause impotence. Similar perceptions have been document in Zambia (28). This change in perception and meanings is similar to what Mary Douglas explains as 'dirt being matter out of place' (48).

Some participants in our study reported the perception of newborns as unclean. This was attributed to the whitish substance (vernix caseosa) that is usually on the skin of newborns. The perception of the newborn as unclean has also been reported in other studies in Uganda (27). Drawing upon Mary Douglas' concepts of dirt and boundaries, substances like spittle, urine and faeces that pass through body orifices are often treated with contempt. It is also a possibility that the view of the newborn as unclean could be due to the traversing of an orifice, usually the vagina, which is regarded as an unclean orifice. Most newborns in our study area were bathed in a herbal solution called *kyogero*, one of whose major purpose was to give blessings. Mothers' stated that if babies are not washed in this solution they turn out to be unlucky, unruly and without blessings. Whether this washing in *kyogero* was related to the perception of newborn uncleanliness, I could not tell.

*Kyogero* is a special and popular herbal formulation worthy of note. It is primarily used for bathing the newborn hence indirectly coming in contact with the umbilical cord, but it's also

directly dropped on the umbilical cord and into the mouth of the newborn. From a biomedical perspective, whereas we fear the possible contamination that *kyogero* might cause, what is of more concern is the repeated use of the same preparation of *kyogero*. As already stated in the findings section, the solution is kept for about one to two weeks and warmed to body temperature prior to bathing the baby, something that could favour bacterial growth and cause infections in the newborn. Infections in the newborn period pose serious risk and are responsible for a quarter of all newborn deaths (7). To attempt and explain why *kyogero* is so popular among mothers in the community and why midwives who are aware of the potential biomedical risks posed by *kyogero* still resort to it, we will draw from Mary Douglas' work on Risk and Culture.

In general, newborn care is structured around averting risks and preventing harm both in the short run and in the long run. In Mary Douglas' perspective, risk assessment does not rest on individuals' cognitive abilities but on socially predetermined assessments, which are politically and morally built (49, 50). To quote Mary Douglas in her book Risk and Blame on page 103 'a refusal to take sound hygienic advice is not to be attributed to weakness of understanding. It is a preference. To account for preferences, there is only cultural theory' (50). Mary Douglas argues that what we may term ignorance in terms of hygiene might merely be a difference in societal or cultural risk assessment. The caretaker looks at all the risks and prioritizes them according to perceived threat. The question could then be why this caretaker prioritizes *kyogero* use? Mary Douglas argues that perspective anger, hope and fear are part of any risk assessment. The benefits of *kyogero* include blessings, cosmetic benefits and immunity from future spiritual and physical ailments. These attributes have one common characteristic, which is hope. The general situation of uncertainty and lack of social security in this community could make hope a vital aspect to keep the communities going. The hope of

a good life in the future, the hope of financial success, the hope of a perfect marriage partner, the hope of a disease free life and the hope of favour among men is embedded in that herbal mixture *kyogero*. Hope is needed to keep people who are facing challenges going, and it would be understandable that a society would prioritize hope ahead of the fear of a childhood infection which many mothers may not relate to. Another possible reason as to why mothers and trained midwives would continue using *kyogero* could be the fear of being blamed and labelled bad parents in case the child turned out unsuccessful or unruly. It might also be that despite the fact that they really relate with the danger of newborn infections, their desire of the added benefits of *kyogero* outweighs the latter. *Kyogero* use makes the recommended use of dry cord care impractical as the umbilical cord inevitably comes into contact with herbs.

Declining access caused by urbanization and deforestation makes *kyogero* more difficult to get as time goes by. This is because *kyogero* is a collection of specific herbs and tree barks, which become rare as cities displace the forests. This trend has also affected the art of *kyogero* preparation, with most young mothers having to rely on older female relatives to get the herbs. So, *kyogero* use might diminish with time. However it is not difficult to imagine an alternative practice replacing *kyogero*. For the health workers and midwives, fighting *kyogero* appears to be a very difficult and probably an unnecessary battle due to the deep rooted cultural ties mothers have with this herbal mixture. The health workers might have to find a way of co-existing with *kyogero*.

Participants also spoke of two disease categories that we could relate to responsible mothering and responsible fathering. Participants talked about *busobe*, which was an illnesses, a child would get if the father had an extra marital affair and then came into contact with the newborn child. This could be seen as a way of discouraging irresponsible fathering in the period in

which both the mother and child are most vulnerable. Participants also talked about an illness they called 'etumbizi' which would affect the child if the child was not covered appropriately. Covering a child can also be seen as a symbol of proper mothering and hence the desire to prevent 'etumbizi' would encourage proper mothering. This could be an attempt of society enforcing desirable traits within its members.

# Chlorhexidine acceptability

The majority of our participants commented favourably about the physical attributes of chlorhexidine: colour, smell and liquid formulation. This is in agreement with a study in Zanzibar, which showed that the 10 ml liquid formulation was the most preferred formulation when they compared it to the gel formulation and the 100 ml bottle (69).

Chlorhexidine use on the umbilical cord has been advocated for as a means of discouraging unhygienic cord practices (25, 27, 43), especially in areas with unacceptability of dry cord care like Uganda and Zambia (24, 25, 27). In our inquiry, we found that acceptance of chlorhexidine for umbilical cord care did not automatically lead to abandonment of all unhygienic practices. Despite appearing willing to abandon the use of certain substances directly applied onto the umbilical cord in favour of chlorhexidine, participants were unwilling to abandon the washing of newborns in kyogero, a herbal mixture, which inevitably comes into contact with the umbilical cord. Chlorhexidine was hence seen as an addition, rather than a substitution, to kyogero use for childcare. The concept of an innovation not automatically displacing the existing practices be explained with implementation deimplementation theory by van Bodegom-Vos et al, which views implementation and deimplementation of a practice as two separate processes that should be actively and carefully planned (70). Bodegom-Vos et al also note that the factors and persons driving implementation and de-implementation could be different. This calls for separate planning sections for implementation and de-implementation. The concept of seeing chlorhexdine as an addition rather than substitution of prior cord practices is also in agreement with Polgar's fallacy of empty vessels. Polgar cautions health promoters not to think that clients or participants are empty vessels waiting to be filled with novel innovations but rather to beware

that they are usually filled with prior beliefs and behaviours which if not addressed could lead to failed interventions (71). According to Polgar's theory, to ignore pre existing beliefs and norms when introducing a new intervention is a grave mistake.

A potential barrier to chlorhexidine scale up into the community is its unfavourable effect of prolonged cord fall off. This has the potential of leading to a communal dislike of the product originating from the influential members of society or opinion leaders. This finding has been objectively accessed in a randomized controlled trial conducted in Bangladesh, which reported a 50% increase in cord fall off time, when chlorhexidine was used (45). A number of authors state that appropriate health communication may ameliorate the negative effect of delayed cord fall off (27, 45). The negative impact of prolonged cord fall may be rooted within deeper socio-cultural meanings attached to the cord, and may not solely be caused by a lack of adequate knowledge concerning chlorhexidine side effects. The findings of negative perceptions among study nurses and midwives who had previously been adequately trained in the chlorhexidine side effect gives credence to our assertion. A number of research nurses/midwives stated that they would not use chlorhexidine on their own children because of the prolongation effect on cord fall off. Prolonged cord fall off also increased the community pressure to resort to the herbal formulations previously used to speed up umbilical cord fall off. This may obliterate the beneficial effects of chlorhexidine in reducing umbilical cord infections. On the other hand, delayed umbilical cord fall off could be beneficial, as newborns and mothers received more nurturing and protection for as long as the umbilical cord was on the baby. Mothers were expected not to leave their newborns unattended, for as long as the umbilical cord was still attached (and therefore their mothers were excused from most outdoor activities as they were expected to stay close to the newborns), and all effort

was made to prevent them from any harm and pain (crying), for as long as the umbilical cord was still attached.

Rogers' diffusion of innovations theory (51, 72) describes how an innovation is taken up by a society. According to Rogers a new product's rate of adoption can be predicted from 5 essential characteristics: relative advantage, compatibility, complexity, trialability, and observability. We will discuss how chlorhexidine faired in the 5 characteristics listed above.

### Relative advantage

Relative advantage is how much better a new product is compared to existing options.

Most participants appreciated the convenience that chlorhexidine brought. The chlorhexidine formulation being advocated for was a onetime formulation that health workers applied on the day of birth. The alternatives for the mother were either herbs, for which they had to rely on older female relatives to provide or substances like salt water, which they had to apply daily and were more of a burden. Most mothers also expressed a mixture of fear and uncertainty concerning umbilical cord care, and would rather have umbilical cord care delegated to someone else, (especially on the first day after birth), as was happening in the trial. However one major setback to the relative advantage was the delayed cord fall off, which seemed to upset a number of participants.

## **Observability**

Observability is how the change the innovation brings is visible to others: the more visible the faster the adoption rate. Participants felt that chlorhexidine quickly shrank the umbilical cord and diminished the foul smell from the umbilical cord. These were the positive results that seemed to be 'observable'. On the negative side, participants observed the delayed cord fall off which discouraged some participants from further use of the product. Most participants

had not lost newborns due to infections and most had not experienced serious infections originating from the umbilical cord.

### **Compatibility**

Compatibility is how compatible an intervention is with the culture and society it is applied in. The more compatible an intervention is, the faster its rate of adoption. Our participants expressed the desire to incorporate chlorhexidine into their existing cultural practices and did not see chlorhexidine as a barrier to their cultural practices. They were quick to point out how the two could work together and this could favour the spread of chlorhexidine. It is important to state that most of our participants were advised not to apply anything on the umbilical cord after the chlorhexidine. However most mothers did not consider this recommendation to include washing the child with herbs or applying products after the umbilical cord had fallen off. The participants interpreted these instructions as accommodative to their cultural practices. Hence chlorhexidine was highly compatible for as long as participants felt that their cultural practices were still permitted.

### **Complexity**

Complexity is how complicated to use an innovation is. The more complicated an innovation the less the adoption of the innovation. Health workers viewed chlorhexidine as very easy to use. Some mothers also mentioned that having seen the health workers apply it, they felt they could also do the same efficiently. The TBAs who were given chlorhexidine also appreciated the ease in using it. Chlorhexidine therefore scored very low on complexity, which, according to Rogers, makes its scale up much easier.

# **Trialability**

Trialability is how readily users can experiment with the innovation: the more they can experiment with it, the better. Most participants did not have the opportunity to try using the product on their own. However TBAs were given the product and they expressed using the product in various different ways. Initially they had been told to only apply it on the first day of birth, but some went ahead to apply it to older newborns. We enlisted TBAs in the study because we regarded them as opinion leaders in the community.

Rogers states that opinion leaders and peers are the most influential persons in persuasion of people towards adoption of an innovation through interpersonal networks (51, 72). As regards umbilical cord care, we noted that during the early newborn period when cord care is needed most women are in isolation and their normal social networks greatly reduced. The persons they have most contact with are caretakers who are usually recruited based on prior childbirth experience and closeness of family ties. These are usually grandmothers/mothers-inlaw/neighbours who end up being the most influential persons in umbilical cord care and hence the opinion leaders. According to Rogers, an opinion leader is usually a trusted member of a community; trusted in his/her superior knowledge about the idea being discussed and trusted to have the client best interest at heart (51). The opinion leader is usually similar to the client in a number of aspects such as social economic status and ethnicity. The opinion leader should also spend a significant amount of time with the clients. The characteristics are easily attributed to the grandmothers/mothers-in-law in our study. They are trusted since they have successfully gone through similar experiences and they would naturally desire the best for their grandchild. In cases where there were no grandparents, it was usually females who had experienced delivery who influenced behaviour.

These older women also differed from the ordinary expected figure of opinion leaders who are usually of a higher social economic status than the average client and who have greater access to external information than ordinary clients.

Indeed, none of the health promotion activities were targeted at these older women who seemed to be the most influential as concerns umbilical cord care. Older female relatives need to be targeted in health promotion drives. They are vital in community newborn care, a finding that has also been observed by other authors (27). Unfortunately, we found that most information concerning newborn care is targeted only to the mothers especially during antenatal and postnatal visits. Efforts need to be made to target these other relatives who usually do the actual care of the newborns in the early postnatal period. In fact, all mothers need to be treated and educated as potential opinion leaders, because the community will soon call upon them to provide advice concerning umbilical cord care. Research evaluating the safety profile of *kyogero* and its interaction with chlorhexidine needs to be conducted.

## Reflection on methods and study trustworthiness

The opportunity to fundamentally inform the RTC through the formative research was not fully utilised. I started the qualitative study only one month prior to the initiation of the RCT. Although I obtained some results that informed the design of the RCT, I realise that this was a very short period and future researchers should aim for longer pre-trial periods.

I triangulated the data collection methods by using IDIs, FGDs and Film, which increased the perspectives and deepened the understanding of the meanings attached to the umbilical cord and to umbilical cord care. Triangulation enhanced the trustworthiness of the findings (58), but observation of umbilical practices around the time of birth would have further

strengthened it. Unfortunately I was unable to organise this during the period I was in the field. I expressed my interests to the TBAs and was told that I would be informed as soon as they got a willing mother, but this did not materialise. This could be because of the sacredness associated with the delivery process, and mothers' reluctance to have strangers witness their delivery moment. It could also be due to the reducing number of mothers that TBAs attend to, as more mothers opt to go to the health facilities. Choosing participants of various backgrounds for examples mothers, health workers and traditional birth attendants is also a way to triangulate (58) and obtain information from different perspectives.

I used an emergent design throughout the research process. Semi structured interview guides allowed deep exploration of participant experiences and room for adjustment of the interview guides as the research progressed, which improves the qualitative interview process (56, 73). Some of interviews were done at the health facilities and this could have affected the responses obtained (73). I was unable to conduct all interviews at places away from the health facilities due to logistical reasons but I tried to look for private places in the facilities and assured the participants of confidentiality, which also increases the trustworthiness of the findings. I was led to our field participants by the help of our gatekeeper and this might have affected the kind of participants we interviewed. During some of the interviews, especially the interviews with the TBAs, the gatekeeper was present and this could have affected the responses we obtained. Since the gatekeeper was a very influential person in the community, study participants may have answered according to what they deemed acceptable to her. However, this was not entirely the case as I often obtained contradicting information to what she had reported in the interviews with her. Social desirability was also a concern in the process of filming the preparation and use of kyogero. Although the film provides a detailed description of the process, the filming was prearranged and the participant may have carefully

prepared to provide information that they deemed appropriate. An impromptu film would have increased the trustworthiness.

We conducted interviews with mothers as they exited the trial a month after the chlorhexidine experience. This time was thought to be sufficient for mothers to have formed opinions about the chlorhexidine experience and yet short enough so that mothers could remember their experiences. Repeat interviews after some time would have been helpful to supplement the findings (75) and check whether the one month period chosen was adequate, but unfortunately I was not able to do this follow up. I did however do member checking (58) with some participants after data analysis to explore whether members identified with some of the themes generated and to also generate more findings as participants interacted with the results. I attempted to pay attention to negative cases by for example searching out mothers who did not like the chlorhexidine experience and giving fair dealing to all perspectives, this also increases trustworthiness (58). As regards the chlorhexidine experience, interviewing participants not involved with the RCT might have given rise to more diverse views though this was not possible in the study setting.

As already mentioned, I anonymized the town studied, a certain health centre, the film and quotes to protect the identity of the participants. This was especially important for TBAs who are no longer legally permitted to conduct deliveries. I provide thick descriptions as I report the entire research process, context and findings to ensure that an audit trail (75) is achievable for interested readers.

As a male doctor interviewing females, I was afraid that the study participants would be shy and not be open about their ideas and practices (73). What I experienced was rather that my

status as a medical doctor was perceived as a source of trust, and hence did not seem to interfere with the responses. Whenever I was asked questions relating to my profession, I would defer them to the end of the interview in order to avoid influencing my participants in the course of the interview (73). As already reported, I was aware of my prior professional experiences, beliefs, motives and assumptions and endeavoured to journal them and bracket them off during the research process to increase trustworthiness (74). I also utilised colleagues, some with no prior medical experience, to read through the interviews, codes, categories and themes as a way of peer examination, which increases credibility (75).

Although efforts were made to obtain trustworthy findings, this study had some limitations.

Although the film provides a detailed description of the process of preparing and use of kyogero, the filming was prearranged and the participant may have carefully prepared to provide information that they perceived as socially desirable. An impromptu film would have increased the trustworthiness.

Having conducted the study in central Uganda where the majority of people of are Baganda, I expect the findings of this study to be transferable to other areas with predominantly Baganda people. The findings from this study could also be transferable to larger group of Bantu ethnicity; indeed similar concepts have been reported in the Ankole of Uganda (27). However it should be noted that many of these practices keep changing and certain practices are abandoned with time.

# **Conclusion**

In this study, the umbilical cord carried symbolic meanings, which extended beyond the newborn and the newborn period, and in turn influenced the various practices of umbilical cord care. Chlorhexidine umbilical cord care was generally accepted due to its convenience, and superiority in the reduction of umbilical cord foul smell and abdominal colic. However, the prolongation of umbilical cord fall off associated with chlorhexidine was a discouraging factor. Despite the willingness to abandon some of the substances previously used for umbilical cord care, participant were unwilling to abandon the practice of bathing the newborn in the local herbal solution *kyogero*, in order to use chlorhexidine exclusively. However, they were willing to combine chlorhexidine with *kyogero* to harness the more holistic benefits of *kyogero*, which include future wellness and blessings. Participants' willingness to defer the bathing of newborns in *kyogero* to a period after umbilical cord fall off, offers a unique opportunity for chlorhexidine health promotion activities. Special attention should be paid to key decision makers like grandmothers and mothers in-law, who are often ignored in the current childcare promotion activities, but were found to be very important in the care of newborns, especially during the first few days after birth.

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# **Appendices**

## **Appendix A: In-depth Interview Guide: Traditional Birth Attendants**

## 1: Delivery and umbilical cord care

What do people in this community do to care for the umbilical cord?

- o What happens during delivery?
- Who decides what is to be done?
- When and how is the cord cut and tied
- o What is applied afterwards and why
- What is applied to the cord stump until it falls off? How frequently? Who applies it? How is it applied? Who decides? Why is it (not) applied? Is anything applied on the rest of the body?

#### 2. Illness in new born

What will happen if you do not adhere to these practices?

- Association with illness
- What kind of illness
- How is that illness managed
- o How can that illness be prevented?

### 3: Umbilical cord meaning

People in different communities attach different meanings and significance to the umbilical cord. What does the umbilical cord mean in this community?

- o Probe about perceived role; physical, cultural and spiritual relevance
- o Probe: What is the reasoning behind it.

What do you do with the umbilical cord after it has fallen off?

Does it have a function also after it is dried and falls off?

- o Is it associated with illness and illness prevention in the newborn?
- o Can it bring misfortune to the household?

ID:	Age:	
Interview date:	Socio-economic status (observe):	
Place of residence:	Interviewer code:	
Marital status:	Tape recording number:	
Region:		
Religion:		
Education:		
Main occupation:		
4. Anything important that we have not touched upon?		
Interviewer comments		

4: Socio-demographic and interview information

### Appendix B: In-depth Interview Guide: Health workers

# 1. Delivery and umbilical cord care

How do people in this community care for the newborn?

- What happens during delivery?
- Who decides what is to be done?
- When and how is the cord cut and tied (mother's expectations and reactions)
- What is applied afterwards and why (mother's expectations and reactions)
- What is applied to the cord stump until it falls off? How frequently? Who applies it? How is it applied? Who decides? Why is it (not) applied? Is anything applied on the rest of the body?
- Are there any other substances that are applied? When, why, by whom, who decides?
- What do mothers who do what have in common?
- Any challenges to current cord care and any solutions?

### 2. Illness in newborn

What will happen if you do not adhere to these practices?

- Association with illness
- Risks related to cord care
- What kind of illness
- How is that illness managed
- How can that illness be prevented?

## 3. Umbilical cord meaning

People in different communities attach different meanings and significance to the umbilical cord. What does the umbilical cord mean to you?

- Probe about perceived role; physical, cultural and spiritual relevance
- What is the umbilical cord?

ID:	Age:
Interview date:	Interviewer name:
Interview start time:	Tape recording number:
Interview end time:	
Place of residence:	
Marital status:	
Region:	
Religion:	
Education:	
Number of years in service:	
5. Anything important that we have no	ot touched upon?

4: Socio-demographic and interview information

**Interviewer comments** 

### Appendix C: Topic guide for FGDs: Mothers / Grandmothers/health workers

Location:
Number of participants
FGD start time:
FGD end time:

## Formulate ground rules together with Informants

-Respect for one another, one person speaks at a time, phones on silent, active discussions, consensus not necessary

## 1. Delivery and umbilical cord care

How do people in this community care for the newborn?

- What happens during delivery?
- Who decides what is to be done?
- When and how is the cord cut and tied?
- What is applied afterwards and why?
- Personal experiences in regards to this issue?
- What is applied to the cord stump before it falls off? How frequently? Who applies it? How is it applied? Who decides? Why is it (not) applied? Is anything applied on the rest of the body?
- What do you think about not applying anything to the cord?
- What do mothers who do this have in common?
- Challenges with cord care and suggestions?

#### 2. Illness in newborn

What will happen if you do not adhere to these practices?

- Risks related to cord care?
- Association with illness?
- Risks related to cord care?
- What kind of illness?
- How is that illness managed?
- Any ways in which that illness can be prevented?

# 3. Umbilical cord meaning

People in different communities attach different meanings and significance to the umbilical cord. What does the umbilical cord mean in this community?

- Probe about perceived role; physical, cultural and spiritual relevance
- Probe: What is the reasoning behind it.
- What do you do with the umbilical cord after it has fallen off?
- Does it have a function also after it is dried and falls off?
- Is it associated with illness and illness prevention in the newborn?
- Can it bring misfortune to the household?
- 4: Socio-demographic and interview information

ID:	Age:	
Interview date:	Socio-economic status (observe):	
Place of residence:	Interviewer name:	
Marital status:	Tape recording number:	
Region:		
Religion:		
Education:		
Main occupation:		

# 5. Anything important that we have not touched upon?

**Interviewer comments** 

# FGD Demographic information sheet

FGD Code:

Please fill in the information requested below			
1	Age		
2	Residence		
3	Religion		
4	Ethnicity		
5	Education level		
6	Last year of School		
7	Income generating activity		
8	Relationship status		
9	Number of children delivered		

### Appendix D: In-depth Interview Guide: Mothers post CHX use

## 1. Delivery and umbilical cord care

How was the umbilical cord of this newborn cared for?

Who decided what was to be done?

When and how was the cord cut and tied (mother's expectations and reactions)

What was applied afterwards and why (mother's expectations and reactions)

What was applied to the cord stump until it fell off? How frequently? Who applies it? How is it applied?

Who decides? Why is it (not) applied? Is anything applied on the rest of the body?

Are there any other substances that were applied? When, why, by whom, who decides?

What do mothers who did this have in common?

Any challenges to current cord care and any solutions?

What illness could result from not taking proper care of umbilical cord?

### 2. Umbilical cord meaning

People in different communities attach different meanings and significance to the umbilical cord. What does the umbilical cord mean to you?

• Probe about perceived role; physical, cultural and spiritual relevance

What is the umbilical cord?

#### 3: Chlorhexidine Use

Was chlorhexidine (a liquid substance) applied to the umbilical cord of your baby immediately after birth?

How did this make you feel?

• Probe: safe, anxious, uncertain

How did the baby react?

How did your husband /caretaker/mother in law/mother feel about it?

Do you think you can apply it yourself?

• Probe: would you be happy if it was added to the mama kit

Where you satisfied with the Chlorhexidine?

• Probe for reason Did you add anything else to the umbilical stump of the newborn? If so what did you apply and what function does it have? How you think other people in your area would perceive it? Compared to your previous experiences with umbilical care, did your practices change after the CHx was applied to your baby? • Probe how What should be improved if this practice is to be rolled out in the entire area? 4. Is there anything of important that I have forgotten to ask? 5: Socio-demographic and interview information ID: Age: Interview date: Interviewer name: Interview start time: Tape recording number: Interview end time: Place of residence: Marital status: Region: Religion:

Would you recommend other people to use Chlorhexidine on their newborns?

Education:

Number of years in service:

**Interviewer comments** 

# Appendix E: In-depth Interview Guide: Health workers CHX acceptability

# 1. Delivery and umbilical cord care

*Interview end time:* Place of residence:

How do you usually care for the umbilical co	ord immediately after delivery
What has been your experience using Chlorho	exidine?
Probe: Do you like color, formulation, and sn	nell? Would you advice any changes
Is it easy to use?	
Is it time consuming? Do you think it increas	es on the workload of the health worker?
Would you encourage mothers to use it or bu	y it?
Would you use it on your own child?	
How has the way you used to care for newbo	rns changed after chlorhexidine was introduced?
What should be improved prior to Chlorhexic	dine roll out?
How acceptable is chlorhexidine to the mother	ers you have used it on?
Have you heard any complaints?	
Have you experienced any situation where th	e mother refused?
If yes, please describe that Experience or us?	
Have the mothers changed the way they care	for the umbilical cord after you apply chlorhexidine? Probe:
Use of other herbs like kyogero	
Is there any modification that you think woul	d make chlorhexidine more acceptable to the mothers?
Do you think mothers can apply it themselves	s?
Who do you think should be applying it? The	mother or the healthworker?
Anything important that we have not touched	upon?
2: Socio-demographic and interview information	tion
ID:	Age:
Interview date:	Interviewer name:
Interview start time:	Tape recording number:

Marital status:
Region:
Religion:
Education:
Number of years in service:

# Appendix F: Topic guide for FGDs: Mothers and health workers

Location:
Number of participants:
FGD start time:
FGD end time:
Formulate ground rules together with Informants
-Respect for one another, one person speaks at a time, phones on silent, active
discussions, consensus not necessary
1. Delivery and umbilical cord care
How do you usually care for the umbilical cord immediately after delivery
What has been your experience using Chlorhexidine?
Probe: Do you like color, formulation, and smell? Would you advice any changes
Is it easy to use?
Is it time consuming? Do you think it increases on the workload of the health worker?
Would you encourage mothers to use it or buy it?
Would you use it on your own child?
How has the way you used to care for newborns changed after chlorhexidine was introduced
What should be improved prior to Chlorhexidine roll out?
How acceptable is chlorhexidine to the mothers you have used it on?
Have you heard any complaints?
Have you experienced any situation where the mother refused?
If yes, please describe that Experience or us?
Have the mothers changed the way they care for the umbilical cord after you apply
chlorhexidine? Probe: Use of other herbs like kyogero
Is there any modification that you think would make chlorhexidine more acceptable to the
mothers?
Do you think mothers can apply it themselves?
Who do you think should be applying it? Is it the mother or the healthworker?

Is there anything important that we have not touched upon?

ID	
ID:	Age:
Interview date:	Socio-economic status (observe):
Place of residence:	Interviewer name:
Marital status:	Tape recording number:
Region:	
Religion:	
Education:	
Main occupation:	

2: Socio-demographic and interview information

# FGD Demographic information sheet

FGD Code:

Please fill in the information requested below

1	Age	
2	Residence	
3	Religion	
4	Ethnicity	
5	Education level	
6	Last year of School	
7	Income generating activity	
8	Relationship status	
9	Number of children delivered	

### **Appendix G: Consent forms**

#### OKW'EYETABYE MUKUNONYEREZA

Omutwe

gw'okunonyereza:

Okunonyereza ku Chlorhexine: Okukkiririza ne Okukolera ddala

kw'Okulongoosa Ekkundi ne 4% Chlorhexidine okuziyiza Endwadde Mubaana

abakazaalibwa mu Uganda: A Randomised Controlled Trial.

Okunonyereza kuno kukolebwa abasawo okuva e Makerere Yunivasite mu Uganda ne Yunivasite ya Bergen mu Norway.

Akulira Okunonyereza:

Musawo Victoria Nankabirwa

Bwebakola Okunonyereza:

Musawo David Mukunya, Pulofeesa James K Tumwine, Pulofeesa Grace

Ndeezi, Pulofeesa Thorkild Tylleskar,

Pulofeesa Halvor Sommerfelt

#### I. Ebyanjula

#### II. Emitendera gy'okunonyereza

Tujja kuba tubabuuza mu Luganda oba Mulungereza okusinzira kukyoyagala era kino kijja kutwala nga eddakiika 60. Amaloboozi agʻokuwayamu kuno gajja kukwatibwa kukatambi amaloboozi okukakasa nti ensonga zonna tuzirina. Tuyinza nʻokukutuukilira era okuddamu okwongera okutegeerera ddala ensonga ezimu ez'emilamwa egy'ogerwako wamu naawe okwetegereza obutuufu bwensongazo nga tuziyuunudde.

#### III. Obulabe

Tewali bulabe eri obulamu bwo olw'okubaweetabye mukunonyereza kuno. Okwetaba mukunonyereza kuno era kulimu okumanyibwa kubyama naye nga kutononnyo ddala. Anonyereza ajjakufuba okulaba nga ekifo awanabeera okubuuzibwa wekusifu bulungi okusobola okukuuma mukyama byonna ebiddiddwamu mukuwayamu era ensonga zonna zijja kukuumibwa bulungi.

#### IV. Emigaso

Tewajja kuba kuganyurwa kwansimbi oba ggwe okuganyurwamu butereevu olw'okubanga weetabye mukunonyereza kuno. Wabula, amagezi aganafunibwa mukunonyereza kuno gajja kuyamba mukukozesebwa okubaga enteekateeka ezinagobelerwa mubyobulamu bwabaana mu Uganda.



1

### V. Okukuuma Ebyama

Ensonga ezikukwatako ng'omuntu ziyinza okukufunibwako nezo ez'omukitundu kyo, era zijja kukuumibwa mukyama ddala, nga zisibiddwa awantu. Ab'omukunonyereza bokka abateekeddwa bebajja okutunulako kubibyo ebikukwatako n'ebyo ebilambe. Ensonga zonna ezitaliko mannya go oba n'endala zonna zijja kwekeneenyezebwa.

# VI. Emiwendo/Okuliyirira okw'okunonyereza

Ojja kuweebwa 10,000 musente eza Uganda ng'okuddizibwawo zokozeseza kuntambula.

# VII. Ebibuuzo ne Okwemulugunya

Singa oba n'ekibuuzo kyonna kukunonyereza kuno oba ng'oyagala okumanya ebisingawo, oba ng'olina obuzibu kuby'obulamu oba ng'olumiziddwa mukunonyereza kuno, olina okutuukilira Musawo David Mukunya kussimu 0775152316 oba Musawo Victoria Nankabirwa kussimu 0755757460.

Bwoba n'ebibuuzo kuddembe Iyo nga nakyeewa eyetabye mukunonyereza, oyinza okutuukilira Akakiiko akavunaanyizibwa kukwekeneenya n'okukwasisa Empisa muby'okunonyereza ak'omuttendekero Iy'obujjanjabi ngoyita mu Amyuka Ssentebe — Musawo Ponsiano Ocama kussimu 0414-533541

Abakozi ab'okunonyereza kuno bajja kuba basanyufu okukuyamba okutuukilira omuntu omutuufu okuddamu ebibuuzo byonaaba olina.

Omukono oba ekinkumu kyo wammanga bitegeeza nti otegeera ensonga ezikutegeezeddwa kukunonyereza kuno n'emukiwandiiko kino eky'okukkiriza okwetaba mukunonyereza. Bwoteeka omukono oba ekinkumu kyo kukiwandiiko kino kitegeeza nti okkiriza ggwe n'omwanawo okwetaba mukunonyereza kuno.

Tolina ddembelyo nalimu Iyonna Iyowayo bwoteeka omukono gwo kukiwandiiko kino.

TUJJA KUKUWA KUKIWANDIIKO EKY'OKUKKIRIZA KINO
Toteekako mukono gwo nga kiyiseko enaku z'omwezi eza:

	3	
Amannya agʻeyetabyemu (Wandiika) Abo abateekako ekinkumu bakka Ni	Omukono oba Ekinkumu ogw'eyetabyemuu	Enaku z'omwezi
. N	kakasa nti eyetabyemu agamba nti amannya g	де уе
	atadde ekinkumu kye kukiwandiiko ky'ol	kukkiriza kino
kubweyagalire kulunaku luno		
4.9	•	* .
Amannya agʻomujjulizi abaddewo ngʻokukkiriza kufunibwa (Wandiika)	Omukono ogw'omujjulizi	Enaku z'omwezi
Amannya agʻomuntu akola nubyʻokukkiriza (Wandiika)	Omukono ogw'omuntu akola kuby'okukkiriza	Enaku z'omwezi
	7 2 2 CO 450	AUG 2017
	2 00000	Eping &

#### RESEARCH PARTICIPANT RECRUITMENT INFORMED CONSENT DOCUMENT

Protocol Title:

The Chlorhexine Study: Acceptability and Effectiveness of Umbilical Cord Cleansing with 4% Chlorhexidine for the Prevention of Newborn Infections

in Uganda: a Randomised Controlled Trial.

This study is being done by doctors from Makerere University in Uganda and from the University of Bergen in Norway.

Principle Investigator: Dr. Victoria Nankabirwa

Co-Investigators: Dr. David Mukunya, Prof. James K Tumwine, Prof. Grace Ndeezi,

Prof. Thorkild Tylleskar, Prof. Halvor Sommerfelt

#### I. Background

#### II. Study procedures

We will conduct interviews in Luganda or English depending on your preference and this will take approximately 60 minutes. The discussion will be audiotaped to ensure that we capture all the information. We may wish to contact you for a follow-up interview in order to gain a detailed understanding of particular aspects of the discussion topics as well as for you to check the accuracy of our interpretation of your experiences.

#### III. Risks

No risks will be posed to your life as a result of this study. Participating in this study also runs a minimal risk of loss of confidentiality. The researcher will ensure that the setting for the interview is private in order to protect privacy of responses generated during the discussion and the information given will be kept very securely.

#### IV. Benefits

There will be no monetary or any direct benefit by taking part in this study. However knowledge generated from this study will help in guiding child health policies in Uganda.

#### V. Confidentiality

Personal information may be collected about you and your community, and it will be kept strictly in confidence, under lock and key. Only the authorized study personnel will have access to your records and personal identifiers. All the information will be reviewed without your name or any other directly recognisable type of information.

#### VI. Costs and compensation

You will be given a compensation of UGX 10,000/= to cover your transport costs

VII. Questions and queries

MAKERERE UNIVERSITY
SCHOOL OF MEDICINE
APPROVED
VALID UNTIL

\*

2 7 AUG 2016

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RESEARCH & ETHICS COMMITTEE P.O.BOX 7072, KAMPALA If you ever have questions about this study, need any more information, or if you have a health problem or are hurt in the study, you should contact Dr. David Mukunya at 0775152316 or Dr. Victoria Nankabirwa at telephone number 0755757460

If you have questions about your rights as a research volunteer, you may contact, the School of Medicine Research and Ethics Committee (SOMREC) through its deputy chairman Dr. Ponsiano Ocama on telephone number 0772421190

ď,

The study staff will be happy to help you contact the right person to answer any questions you have.

Your signature or thumbprint below means that you understand the information given to you about the study and in this consent form. If you sign or place your thumb print on this form, it means that you agree that you and your baby will take part in the study. You are not giving up any of your legal rights by signing this informed consent document.

WE WILL OFFER YOU A COPY OF Do not sign after the expiration dat	THIS CONSENT FORM.	
Participant's Name (thumb print)	Participant's Signature or Thumb Print	Date
For those placing thumbprint only: I attes	t that the participant who states that her name is	
consent form of her own free will on this	has placed her thumbprint on this	
Name of Witness to Consent Process (print)	Witness' Signature	Date
Name of person obtaining consent (Print)	Signature of person obtaining consent	Date
	MAKERERE UNIVERSIT SCHOOL OF MEDICINE APPROVED VALID UNTIL	*
	RESEARCH & ETHICS COMMI P.O.BOX 7072, KAMPA	LA

#### Appendix H: Ethical clearance



#### Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS 1927

Victoria Nankanbirwa Makerere University Kampala

Re: Research Approval:

Acceptability and Effectiveness of Umbilical Cord Cleansing with 4% Chlorhexidine for the Prevention of Newborn Infections in Lira District, Northern Uganda: A Randomized Controlled Trial

I am pleased to inform you that on 02/11/2015, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of 02/11/2015 to 02/11/2018.

Your research registration number with the UNCST is HS 1927. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval

- All co-investigators must be kept informed of the status of the research.

  Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval prior to the activation of the changes. UNCST must be notified of the approved changes within five working days.

  For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review
- with copies to the National Drug Authority.

  4. Unanticipated problems involving risks to research subjects/participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST review.

  5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study
- 6. A progress report must be submitted electronically to UNCST within four weeks after every 12 months. Failure to do so may result in termination of the research project

Below is a list of documents approved with this application

	Document Title	Language	Version	Version Date
1.	Research Proposal	English	N/A	N/A
2.	Consent Forms	English and Langi	N/A	N/A
3.	Storage Consent Forms	English and Langi	N/A	N/A
4.	Questionnaire	English	N/A	N/A

Yours sincerely,

Hellen .N. Opolot

for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

cc. Chair , College of Health Sciences , School of Medicine Research Ethics Committee

LOCATION/CORRESPONDENCE

COMMUNICATION

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