Perinatal deaths in Lusaka, Zambia: Mothers' experiences and perceptions of care.

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Declaration

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1. LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ARH	Adolescent Reproductive Health
BCC	Behavior Change Communication
BMJ	British Medical Journal
CBOH	Central Board of Health
CBOs	Community Based Organizations
CHW	Community Health Workers
CSO	Central Statistical Office
DFID	Department of International Development
DHO	District Health Office
DHS	Demographic and Health Survey
EONC	Essential Obstetric Newborn Care
EmONC	Emergency Obstetric and Newborn Care
FANC	Focused Antenatal Care
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
HRH	Human Resources for Health
HW	Health Workers

IMDA	Investigate Maternal Death and Act
IMR	Infant Mortality Rate
IP	Infection Prevention
IRH	Integrated Reproductive Health
IRB	Institutional Review Board
IYCF	Infant and Young Child Feeding
MCH	Maternal and Child Health
MDGs	Millennium Development Goals
MCH	Maternal Health
MNCH	Maternal Newborn Child Health
MMR	Maternal Mortality Ratio
MMR	Maternal Mortality Rate
MOH	Ministry of Health
MOU	Memorandum of Understanding
NGOs	Non-governmental organizations
NHC	Neighborhood Health Committee
NHSP	National Health Strategic Plan
NMR	Neonatal Mortality Rate
PHC	Primary Health Care
PPP	Public Private Partnership

RH	Reproductive Health
RHC	Rural Health Center
RHL	Reproductive health library
SMAG	Safe Motherhood Action Group
SMGL	Saving Mothers Giving Life
SMS	Short Message Sending
SMI	Safe Motherhood Initiative
SNDP	Sixth National Development Plan
TBA	Traditional Birth Attendant
TTBA	Trained Traditional Birth Attendant
U5	Children under the age of five years
UCT	University of Cape Town
UNDP	United Nations Development Program
UNFPA	United Nations for Population Agency
UNICEF	United Nations Children's Fund
UNZA	University of Zambia
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
ZDHS	Zambia Demographic and Health Survey

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3. ABSTRACT

Perinatal deaths in Lusaka, Zambia: Mothers' experiences and perceptions of care.

Objective: To explore and analyse mothers' personal experiences and perceptions of care around the time of a perinatal death and early neonatal death in health facilities of Lusaka.

Purpose: This study focused on the experiences, perceptions and needs of women who experienced perinatal loss in a health facility in Lusaka, Zambia. The purpose was to analyse aspects of care and support services received by these women and to make recommendations for appropriate service design.

Research Design and Method: A purposive sampling method was adopted using a social mapping strategy where ten women above the age of 18 years were selected. A qualitative design was used to enable participants to talk about their perceptions of care and support around the time of a perinatal and early neonatal loss. Data were collected using unstructured interviews following a question guide. The interviews were captured verbatim using a tape recorder and were later transcribed. The results were interpreted through a Grounded Theory methodology that induced reasoning and developed theories grounded from the data gathered.

Results: A total of ten mothers individually shared their perceptions of care and support. The analysis of the interviews resulted in the identification of six themes namely; following advice of friends and relatives, referral for specialist care, inadequate emergency care, neglectful and disrespectful care, poor communication and the need for psychosocial and emotional support.

Conclusion: The study revealed that perinatal loss is emotionally devastating and difficult for the mother. The study further revealed that psychosocial and emotional supportive services are either unavailable or are not fully utilised. These issues have received little attention from policy makers and health providers. The findings give rise to several recommendations for improving community, clinical care practice of nursing and health care support services.

KEYWORDS: **Neonatal mortality, perinatal mortality, stillbirth, loss, live birth.**

4. DEFINING CONCEPTS

4.1 Neonatal mortality

This refers to death of a baby occurring during the first four weeks after birth. The neonatal period begins with birth and ends 28 complete days after birth. Neonatal deaths may be subdivided into *early neonatal deaths*, occurring during the first seven days of life (0-6 days), and *late neonatal deaths*, occurring after the seventh day but before the 28th day of life or between 7-27days (WHO 2006).

4.2 Perinatal period

This is a period commences at 22 completed weeks (154 days) of gestation and ends seven completed days after birth (WHO 2006).

4.3 Stillbirth

This is a professional and lay term that refers to a dead born fetus after 24 completed weeks of pregnancy (WHO 2006).

4.4 Perinatal death/ perinatal mortality

This is cessation of neonatal life within 0-6 days or within the first week of life after 20 completed weeks of fetal gestation (WHO 2006).

4.5 Loss

This is an experience of something meaningful being taken away, which threatens an individual's level of comfort and well-being and which may result in uncomfortable physical and psychological feelings (WHO 2006).

4.6 Live birth

A product of conception which, after complete extraction from its mother, shows signs of life such as breathing, beating of the heart, umbilical cord pulsation or spontaneous movement of voluntary muscles regardless of gestational age and whether the cord has been cut or the placenta has been extracted or not (Zupan 2005).

5. INTRODUCTION

The World Health Organization (WHO) and other United Nations (UN) agencies cited global estimates indicating that over four million babies die in the first four weeks of life every year (UNICEF 2012, WHO 2006). It is further estimated that more than 3.3 million babies are stillborn every year while one in three of these deaths occurs during delivery largely due to preventable causes. Of all stillbirths/perinatal deaths 98 per cent take place in the developing world, with 1.16 million occurring in Sub-Saharan Africa and stillbirths accounting for over half of all perinatal deaths (Lawn & Kerber 2006, Lawn et al 2011, UNICEF 2012, WHO 2006).

In Africa alone, one(1) in five(5) mothers will experience the death of a newborn, whereas less than one(1) in a hundred (100) mothers will do so in developed countries (Save the Children 2006). Neonatal mortality rates in the African Region is the highest in the world and based on conservative estimates, perinatal mortality rate in the Sub Saharan region is 76 per 1000 live births (WHO 2002). In most low resource settings, for example, in Zambia, there is likelihood for gross underestimation of perinatal deaths due to significant under-reporting and inadequate reporting systems, especially for home deliveries at community level (CSO 2007, Joseph 2007). The Central Statistical Office (CSO) in Zambia has shown perinatal mortality rate to be 38 deaths per 1,000 pregnancies (CSO 2007).

While most maternal newborn deaths are avoidable, many die each year due to complications during pregnancy and childbirth. A study employing the Investigate Maternal Deaths and Act (IMDA) approach in Zambia found most maternal newborn deaths were associated with poor communication, client high risk factors, lack of resources and issues related to case management, poor communication between health facilities, delayed treatment and reduced preparation time for referrals in emergency situations (Hadley & Tuba 2011). Another study conducted in Kalabo District of Zambia found that 96 per cent of

women preferred to deliver in a clinic as opposed to only 54 per cent who managed to deliver in a health facility. The reasons cited for this variance were long distances, lack of transport, user fees, inadequate health education given during antenatal clinic attendances, poorly staffed and ill-equipped institutions with unskilled health providers (Stekelenburg et al. 2004). This scenario has further been linked to delays in recognizing the problem, delays in arranging transportation to the health facility and delays in accessing and being provided with appropriate care at the facility (Thaddeus 1994).

In the recent years, a lot of attention has been placed on improving maternal and newborn health as part of the count down towards achieving Millennium Development Goals (MDGs) by 2015. The launch of *Every Woman, Every Child* strategy at the United Nations summit in 2010 has been one such example of mobilizing over 200 commitments from national governments, non-governmental organizations (NGOs) and the private sector with the aim of saving lives of 16 million women and children by 2015 (WHO & UNICEF 2012).

5.1 Justification for the Study

The period soon after childbirth poses substantial health risks for both mother and newborn infant. Yet the postpartum and postnatal period with subsequent neonatal losses receive less attention from health care providers than pregnancy and childbirth (WHO 2006). Consequently, the emotional and psychosocial aspects of perinatal death for the mother has received negligible attention in low resource settings as the bulk of research and health planning attention has focused on technical aspects of antenatal, labor care and delivery (WHO 2005).

The research for this study is located within Zambia but may be relevant to countries in Sub- Saharan region of Africa because of the high rates of perinatal deaths and the associated high numbers of mothers facing these losses in this region. For many of these women, these losses have a significant impact on their

emotional and psychosocial health and wellbeing (UNICEF 2012, WHO 1998). Furthermore, WHO and UNICEF have reported that quality of care delivered by health care staff in labor rooms and wards in many low resource countries was usually compromised for reasons such as inadequate midwives and doctors staff, inadequate equipment and supplies, poorly managed health systems and a human resource crisis due to brain drain (UNICEF 2012, WHO 2005).

Against this background, this dissertation examined mothers' experiences and perceptions of care during pregnancy, labor, delivery and the early neonatal period immediately after delivery subsequent to the death of their babies. Ten women who had experienced a perinatal loss and early neonatal loss were interviewed to establish their account of the events as well as their views regarding care and support services rendered in connection to the losses. The aim of the research was to assess and analyze prevailing situation regarding care and support services from the mothers' perspective. Information gathered generated relevant recommendations for local situation in Zambia applicable for providing quality health care for mothers in low resource settings.

5.2 Research Questions

1. How did mothers, delivering in a health facility, perceive health and supportive care after perinatal loss?
2. What support needs and services did mothers experience immediately after the loss of baby, during their stay in hospital up until discharge from the health facility?

5.3 General Aim

The study explored and analysed the kind of health care experiences, and services that mothers received antenatally, during labour, delivery and in the early postnatal period in Lusaka, Zambia.

5.4 Objectives

1. To explore and analyse mothers' personal experiences and perceptions of care support around the time of a perinatal loss in a health facility.

2. To explore and analyze factors associated with access to support services for mothers following perinatal loss in a health facility.

6. LITERATURE REVIEW

6.1 Introduction

In reproductive health, perinatal and neonatal mortality rates are largely used as indicators to assess and analyze quality of antenatal and perinatal care being provided to pregnant women and newborns (Mathews & MacDorman 2008, Pittrof 2002). The loss of a baby prenatally has been described as the most painful and devastating event a mother or any parent can experience. This type of loss in particular given that parents' expectations and joy at the prospect of a new life suddenly changes into despair and grief (Milo 1997, Radestad et al. 1996).

Perinatal loss is a phenomenon where, by virtue of the biological attachment, a woman experiences the death of another literally inside of her or immediately after delivery (Wittwer 1994). This presents as a physiological and physical loss due to cessation of sensation of the unborn child moving inside the mother's womb, turning into a significant loss of her body's functional adequacy and associated feelings of self-worth (Aldofsson et al. 2004, Talbot 2002). Some researchers have emphasized that every parent experiences grief differently and there is usually a lack of understanding by the general public on how to deal with this type of grief. Consequently, grief of this nature may be suppressed or deferred and could be worsened by inadequate or no support (Moody & Arcangel 2002, Chumbley 1997).

The psychological and mental well-being of women during the perinatal period ought to be recognized as an important aspect of maternal health. In Zambia, women's mental health, especially during the reproductive period, is an aspect which has not been fully included as part of the continuum of care (Mwape et al. 2010). This is visible in clinical protocols, algorithms and screening processes of women during the antenatal and postnatal periods. Unless, there is a deliberate provision of psychosocial mental health care with supportive interventions, a

woman encountering a perinatal loss is left unsupported which impacts negatively on her general health status (Raphael 2009, Maimbolwa 2004).

There is minimal and scattered research on the emotional and social experiences of mothers experiencing perinatal loss in low resource settings. Furthermore, there appears to be inadequate documentation on appropriate interventions and support services for addressing the psychological ill- effects of perinatal loss in the same environments. This is in contrast with the abundance of literature on clinical services made available during antenatal care.

To facilitate my research study, I searched for any available literature and published information on maternal newborn health care and support services offered to women following a perinatal loss in health facilities in developed and developing countries, with a special focus on the sub-Saharan region. An electronic search was conducted for publications, such the journals: the Lancet, British Medical Journals, Reproductive Health Library, Cochrane reviews and trials and Advanced Nursing Journals. I also searched for relevant research articles, policy documents, abstracts and references that were frequently cited by other authors including additional literature, abstracts and journals recommended by colleagues and my supervisors.

6.2 Epidemiology of perinatal and neonatal death:Western countries, Africa and Zambia

In reproductive health, perinatal mortality rates are generally used to reflect the quality of prenatal, delivery and early infant care practices available in any setting (Mathews & MacDorman 2008, Pittrof 2002, WHO 2005). Though perinatal mortality rate is a useful indicator of the quality of antenatal and perinatal care, making a global statement of this nature is potentially misleading as various determinant factors specific to differing environments are at play and these need to be assessed separately before reaching conclusions about quality of care issues (Lawn et al. 2005).

Perinatal mortality rates in developed countries are below 10 for every 1000 live births, whereas in sub-Saharan Africa, this has been shown to be between 40 and 120 for every 1000 live births (WHO 1996). Globally, four million babies die annually in their first four weeks of life, with 99 per cent of these deaths occurring in low-and middle-income countries. Thirty per cent are neonatal deaths in Sub-Saharan Africa followed by Asia and latin America (UNICEF 2008). A large proportion of stillbirths in most low resource settings are not documented because the majority of births take place at home (Lawn et al. 2005, UNICEF 2009, Zupan 2005). However, factors associated with these deaths are directly due complications of preterm birth, asphyxia, birth trauma, infections and severe congenital malformations account for majority of the deaths, in South –Central Asia and Sub-Saharan Africa (Black et al. 2010).

Indirect causes include poor or inadequate nutrition in mothers either early in childhood or later in life which may lead to delivery of low birth weight babies - one of the significant contributors to perinatal mortality. Another indirect cause is poor maternal education which is not only associated with poor nutrition but also poor health seeking behaviour and poor perinatal outcome. Furthermore, certain maternal health conditions such as pregnancy-induced or essential hypertension, diabetes mellitus, anaemia and infections such as malaria, Acquired Immune Deficiency Syndrome(AIDS) and tuberculosis, predispose to intrauterine growth retardation, low birth weight and perinatal death. Birth spacing of less than two years birth interval has also been known to contribute to poor maternal nutritional reserves that predispose women to low birth weight infants and perinatal death. High maternal parity and extreme conception age of less than 18 years and greater than 45 years are associated with poor birth outcomes and perinatal morbidity and mortality. Low socioeconomic status of the mother has been shown to be associated with higher perinatal mortality rate (Black et al. 2010, Hoque et al. 2011, Lawn et al. 2005, Zupan 2005).

Some studies in low income countries have shown that a large proportion of perinatal deaths occur in women who did not receive antenatal care during pregnancy and hence missed out on effective maternal interventions such as micronutrient supplementation, intermittent presumptive treatment (IPTp) of malaria and tetanus toxoid vaccination offered during the antenatal period (Black et al. 2010, Hoque et al. 2011, Lawn et al. 2005, Zupan 2005).

Inadequate supervision during labour in a hospital setting and deliveries conducted outside a health facility by unskilled birth attendants contribute to stillbirth delivery and neonatal death. Labour rooms lacking resuscitation equipment and unskilled personnel contribute to birth asphyxia which eventually leads to death. Unsanitary and unhygienic labour rooms are associated with early neonatal sepsis and mortality (Black et al. 2010, Hoque et al. 2011). Prenatal complications such as antepartum haemorrhage secondary to placenta praevia or abruptio, pre eclampsia or eclampsia all predispose to foetal loss. Other complications during labour and delivery such as cord prolapse and uterine rupture may lead to still births or birth asphyxia. Multiple pregnancies are associated with preterm delivery and low birth weight which are leading causes of perinatal morbidity and mortality (Bhutta et al. 2005, Duysburgh et al. 2013, UNICEF 2008, Zupan 2005).

Once discharged from hospital, additional determinants of neonatal loss are poor maternal health seeking behaviours and harmful home care practices, such as the discarding of colostrum, the application of unclean substances to the umbilical cord stump, and the failure to keep babies sufficiently warm, inadequate maternal nutrition, early childbearing and closely spaced pregnancies putting new-born babies at risk (Black et al. 2010, Hoque et al. 2011).

Zambia is one of the countries with the highest child mortality rates in the world. According to Central Statistical Office (CSO) following the Zambia Demographic Health Survey (ZDHS) conducted 2007, for the period 2002 to 2007

infant Mortality Rate (IMR) reduced from 95 per 1000 live births to 70; and under-five Mortality Rate (U5MR) reduced from 168 to 119 per 1000 live births. While neonatal deaths constitute approximately half of the number of infants who die, the reduction in neonatal mortality over that period remains insignificant, from 37 to 34 per 1000 live births. This has lead to concerns about the quality of perinatal care in the country (CSO 2007).

6.3 Service delivery factors associated with perinatal loss.

Thaddeus and Maine(1994) outlined three common delays in accessing quality maternal care namely: (1) delay in recognizing illness and decision to seek care; (2) delay in reaching an appropriate source of care and (3) delay in receiving adequate care. Other researchers have used the same framework to understand the major contributing factors to newborns deaths in their contexts. For example, the three delays model was applied to auditing of data on 64 neonatal deaths in eastern Uganda that found delayed care-seeking to be the predominant factor in newborn mortality (Waiswa et al. 2010) whereas in Tanzania and Gambia, receiving quality care and reaching an appropriate care facility was found to be the leading delay resulting in newborn deaths (Mbaruku et al. 2009, Jammeh et al. 2011).

From a study conducted in Kalabo District of Zambia in 2004 to assess service delivery, it was discovered that although ninety six percent of women preferred to deliver in a clinic, only fifty-four percent managed to do so. This was because of long distances, lack of transport, user fees, lack of adequate health education during antenatal clinic attendances and poorly staffed and ill-equipped institutions with inadequately skilled personnel (Stekelenburg et al. 2004). These challenges have also been identified in Zimbabwe where it was noted in a study that hospital attendance increased in the third trimester of pregnancy. These women mostly attended due to complications and ill-health and consequently experienced poor birth outcomes (Lawn et al. 2006, Lawn et al. 2011). Poor birth

outcomes have generally been associated with a failure of health personnel to monitor pregnancy and labor and their inability to use timely life-saving interventions such as fetal heart rate monitoring and the partogragh (Lawn et al. 2006).

Other contributory factors impacting the quality of perinatal service delivery in health institutions include the following:

6.3.1 Inadequate skilled birth attendants

Saving the lives of mothers and babies depends not only on high coverage of essential health services, but also on the quality of care, capacitated health personnel, adequate emergency drugs and availability of a viable referral and emergency health system. Having such a workforce in place entails training and supervision in order to meet health needs, assist nursing and medical staff to manage their workload more effectively without creating burn out (Honikman et al. 2012, Pittrof et al. 2002). In Zambia and the majority of low resource settings, human resource crisis is a major factor perpetuating inefficiencies and inequities in the health sector and severely weakening health service delivery (WHO 2006). Rural, hard to reach remote areas have been the worst affected by low numbers of health workers, poor work environments and unsupportive supervision (CSO 2007). Health workers' motivation levels and performance are thus negatively affected resulting in poor quality or inadequate care, poor staff attitudes and eventual poor health outcomes (Jewkes et al. 1998, WHO 2006). In contrast, it has been shown that maternal and neonatal mortality rates are lower in countries where there is easy access to skilled professional care and well-equipped facilities offering effective and timely management of complications (Graham et al. 2001).

6.3.2 Inadequate Emergency Obstetric and Newborn Care (EmONC)

A well-organized health system with adequate skilled health workers providing timely emergency obstetric care play critical roles in EmONC by saving the lives of women with obstetric complications during pregnancy, labour and delivery and save newborn lives intrapartum (Prata et al. 2011). Unfortunately, EmONC gaps such as inadequate skilled staff with EmONC training, inadequate or non-availability of drugs, equipment and supplies constitute barriers to accessing quality maternal and neonatal care. Women may not seek delivery or life-saving obstetric care at facilities if they know that staff or services are not available. Other deterrents to accessing facilities by mothers are the inability to pay the required fees for services or purchase the basic maternity requirements for services at a hospital or health clinic. Furthermore, perceived mistrust, misconception of care at the facility by the mothers and lack of understanding of cultural beliefs and practices by staff may discourage care seeking behavior (Ngomane & Mulaudzi, 2010, Stekelenburg et al. 2004).

The Ministry of Health in Zambia working in collaboration with other implementing partners namely; Non-governmental Organisations (NGOs) and Civil Society Organisations (CSOs) adopted the Emergency Obstetric and New-born Care (EmONC) intervention as its main strategy for managing obstetric complications(MoH 2011). This was in response to findings from the 2005 EmONC Needs Assessment that revealed various challenges mentioned above. Zambia also experienced an erratic supply of essential drugs and medical supplies during the period 2006 to 2008 (MoH 2011). Availability of medical equipment and supplies improved to over 80 percent with the emergence of new programs. By the end of 2012, there were more than 61 districts with 768 health workers trained in the provision of EmONC services. Facilities where strengthened with the provision of necessary medical equipment. Within the same assessed district, a total of 368 facilities were upgraded into EmONC facilities and were expected to provide the necessary EmONC services (MoH 2005). Non-theless, limitations in human resources, weak supply chain management at certain levels, growing demand on services, and a lack of

appreciation of logistics functioning in the health delivery system have continued to negatively affected EmONC performance.

6.4 Mothers' perinatal loss experience

Globally, until the 1980s, babies who died in the perinatal period were quickly removed from the mother's sight and any discussion regarding the baby and its death was often considered taboo (Gilbert & Smart 1992, Lewis & Page 1978). It was further believed that bonding between the mother and the baby only began after birth and that staff preventing parents from seeing the baby, were able to prevent any development of any emotional attachment and thus protected parents from unnecessary pain, grief and distress (Boyle 1997, Gilbert & Smart 1992, Tunney 1994).

However, in recent decades, these notions have dramatically changed. The mothers' wishes and desires are increasingly being respected and honored (PLIDA 2008, RCOG 1985, RCOG 2010). This derived from the understanding that physical contact and having memories of the dead baby may ease the grieving process and enhance recovery (Lewis 1979). Granting these changes, other studies have described women's emotional feelings of disappointment, guilt, failure, embarrassment, emotional cocooning, inadequacy, anger and blaming someone or something for their loss such as God, a member of the medical profession and even themselves (Kavanaugh & Hershberger 2005, Van & Meleis 2003). Some differences in expressing grief between men and women have been noted suggesting that, women have difficulties talking about their grief whereas men have difficulties expressing their emotions and managing the emotions of their spouses (Feeley & Gottlieb 2000). In other studies, perinatal grief has been associated with marital discord and the creation of ill-effects on the marital relationship (Gilbert 1987, Wallerstedt & Higgins 1996). Some parents become fearful and dread attempting a subsequent pregnancy (Kavanaugh & Hershberger 2005, Van & Meleis 2003). Whereas other women experienced an

overwhelming desire and need to become pregnant again (Limbo and Wheeler 1998).

Research conducted in westernized environments, revealed that mothers experienced various emotional phases such as avoiding discussions and thoughts regarding the loss, attempting to find meaning and comfort with thoughts that the baby had been taken to good place, based on their spiritual and religious beliefs. It was shown that those mothers who received mementos such as name tags, pictures and planned a funeral service were comforted, though plans for subsequent pregnancies brought fear and anxiety (Van, 2001, Van & Meleis, 2003).

Much of what has been written about developing countries regarding mothers experiences with perinatal loss has been based on assumptions from westernized methods that do not consider differing cultural and traditional beliefs as well as environmental factors in low resource settings (Tunney 1994). Generally in the rural areas of Zambia, there are various cultural beliefs and superstitions that surround complicated pregnancies, birth and early child care.

Much of what has been written about developing countries regarding mothers experiences with perinatal loss has been based on assumptions from westernized methods that did not consider the differing cultural, traditional beliefs and environments in which family life styles and children rearing practices have emerged in low resource settings (Tunney 1994). Generally in the rural areas of Zambia, there are various cultural beliefs and superstitions that surround complications in pregnancies, labour, delivery, child birth and early child care.
Delivery complications are considered punishment for extramarital affairs (Maimbolwa et al. 2003). In the event of obstructed labor, the mother is left in prolonged labor and advised to confess any extra marital sexual encounters she may have engaged in because this is believed to be the cause for prolonged obstructed labor and resulting possible stillbirth. If she confesses, she will be

given traditional herbs as medicine to assist with the labour. If the mother survives, the prolonged obstruction can result in an obstetric fistula—a hole that arises between the vagina and the anus or bladder that causes uncontrollable leakage of urine and faeces (Nsemukile et al. 1998). This complication is widespread throughout sub-Saharan Africa and cause social ostracism, abandonment as well as chronic health problems and subsequent birth complications (Nsemukila et al. 1998, Maimbolwa 2013, WHO 2010).

After the demise of a baby in the rural areas, the mother is not allowed to cry for this loss as it is believed that the baby just passed through the world without stopping over. The baby is buried quickly in the village. If it is in a hospital setting, and depending on the cause and type of birth, the mother is asked to choose whether the baby should be incinerated or whether the family would like to have a burial. If the latter is desired, the mother will only be discharged after the burial and will not be present for the ceremony. Women during this time are considered unclean and it is a tradition for people not to greet the bereaved mother with a traditional hand shake, for fear of being contaminated (Nsemukile et al. 1998, Siziya & Hazemba 2009). A number of beliefs and traditional practices have changed overtime especially in the urban areas because of increased awareness about gender issues and rights of women.

In the last two decades, there has been an emergence of literature and management protocols for good practice in the labour wards, though mostly arising from western countries (Ngomane & Mulaudzi 2010). However, especially given high perinatal mortality rates, there is a gap in knowledge about Zambian mothers' experiences and preferences relating to perinatal loss. The purpose of this study therefore was to explore and analyse experiences and perceptions of 10 mothers who had perinatal loss at a health facility. Information gathered is intended to inform recommendations to address health care and support service gaps for improved holistic maternal health care.

7. METHODOLOGY

7.1. Introduction

For this study on mothers' experiences and perceptions, I adopted a qualitative methodological approach using semi-structured interviews. The data was interpreted using a Grounded Theory theoretical framework.

7.2. Choice of method and theoretical framework

For the purpose of generating data from mothers' experiences of a perinatal loss in a facility in Lusaka, I chose to use qualitative research methodological approach. This research methodology was chosen to gather rich and detailed data pertaining to the experiences of mothers, drawing on their own personal perspectives and knowledge. Information was collected through semi-structured interviews which placed emphasis on the personal perspective, interpretation and meaning from the participants' individual point of view (Emmel 2008, Schwandt 2001).

I decided to use this methodology because, firstly, it is exploratory in nature and data was gathered from the perceptions of affected women themselves. Secondly, the use of individual interviews is encouraged in qualitative studies because it facilitates collection of personalized information. Thirdly, engaging with mothers interactively increased in-depth gathering of information. This method was considered better than having controlled measurements and undertaking statistical analysis (De Vos et al. 2004, Seidel & John 1998).

The Grounded Theory (GT) theoretical framework was used in order to ensure an in-depth understanding and analysis of women's experiences and for GT's suitability for investigating and understanding real-life situations. GT was originally developed by two sociologists Barney Glaser and Anselm Strauss in the 1960s. It is now widely used by a number of researchers particularly in the health sciences as it provides well-established procedures for dealing with

large quantities of unstructured data (Glaser & Strauss 1967). The GT framework uses an inductive approach to gather data and allows research findings to emerge from the frequent, dominant or significant themes inherent in the raw data (Benoliel 2001, Glaser & Strauss 1967).

I was further encouraged to use GT after reading other similar studies conducted that adopted this framework. For example, studies into implementing improved caring practices in a hospital in Benin (Fugita 2011) and another that investigated processes of preventing tooth decay in a dental practice in New South Wales in Australia (Sbraini et al 2011). Therefore, theory generated from data gathered in this research study is expected to be applicable to nursing care practice since it is grounded in the words of the women who experienced pregnancy loss (Benoliel 2001, Glaser 1992).

7.3. My role as researcher

Being a professional nurse with a personal experience of perinatal loss, the initial introductory stage of conducting the interviews was both intellectually and emotionally challenging and thought-provoking. The conversational nature of the interview was particularly difficult when coupled with the task of being the research instrument through which data was being collected, filtered and processed. As a nurse, student, researcher and previous patient, I was conscious of the possibility of influencing the interview process or misconstruing the participants' perceptions and concepts being explored and imposing my own values and beliefs in the interpretation.

In order to establish rapport with the mothers, I chose to introduce myself and indicate my profession of being a nurse. I also explained that I had had a similar experience in order to create an environment of trust, discretion and to reassure about matters of confidentiality. Whilst this may have conferred an advantage in terms of the quality of my engagement with my participants, researchers' openly

identifying with participants has been shown elsewhere to be a detriment, depending on respondents' previous health facility encounters with health professionals (Hewitt 2007, Schutz 1994). I observed no negative reactions to disclosing my professional status and personal experience. However, I was aware of the possibility of the researcher and the respondent's capacity to influence or be influenced in the process of social interactive interview (Hutchinson 1994).

7.4. Study design

7.4.1. Sampling

In this study, purposive sampling technique was used as the intention was not to obtain a representation of a population but to have a sample size with as similar characteristics as possible. This form of non probability sampling process was conducted based on an already identified inclusion and exclusion crieteria detailed below. This sampling method was also used because of the practical benefits of reduced cost and time and the suitability for the focus of understanding complex social phenomena in a particular group of women (Dongre et al 2009).

7.4.2. Sampling strategy and recruitment

The sample of 10 accords with the qualitative methods approach, that allows for in-depth investigation of data from small sample. The sample size was selected for logistical reasons. I used my exisiting social networks to identify potential participants. This process facilitated the acquisition of samples for investigative purposes rather than to statistically represent a population (Emmel 2008, Ritchie et al. 2003). These included relatives, colleagues, neighbors, churchmates and friends. Prior to my initial engagement with the women, I requested my network contact person to enquire of the potential respondent, in a non coercive way, whether she would be willing to be interviewed about her perinatal loss experience. The process of initiating contact with the mothers upon

recommendations from the network was helpful as this seemed to alleviate any anxieties mothers may have had by being contacted by an entirely unknown researcher. Initial contact with potential particpants was made over the telephone in order to arrange the first appointment and also to maintain privacy and confidentiality, should the potential particpant be uncomfortable with the approach. Prior to the interviews, I explained the nature of the study to each participant. Each particpant was given an opportunity to decide from which location they wanted to be interviewed. The majority preferred to be interviewed from their homes whilst a few chose to be interviewed from their workplaces and a few preferred the shopping mall.

The research was conducted in Lusaka, the capital city of Zambia. The city was purposely chosen because of the mixture of government, private hospitals and clinics available (Appendix 5: Government facility and maternal services offered), the presence of public and private health institutions for health professional training and the high numbers of skilled professional health providers (CSO, 2007). The particpants were not recruited at any clinics or health facilites.

7.5. Ethical considerations

Prior to conducting research, the research protocol was sent to the University of Cape Town (UCT), Faculty of Health Sciences Human Research Ethics Committee (HREC) for Ethical approval. Upon obtaining clearance from this body (Attached - Reference number 294/2011), the research protocol was then taken to ERES CONVERGE, an independent recognized Institutional Review Board (IRB) in Zambia. It was only after clearance was obtained from ERES CONVERGE (Attached - Reference number 2012-April-001), that data collection commenced.

The study posed emotional risks to study participants and these were observed during the process of their narrating their personal experiences. The process did

initiate latent distressing emotions for some women. This is because it was difficult to divorce the mothers' experience of care and support from the loss itself. In anticipation of such emotional responses, existing support and social services currently available in Lusaka were identified. In addition, a doctor and two nurses agreed to offer counseling services in the event that any of the participants required urgent psychosocial and emotional support during the research period.

The counsellors' details and designations were compiled, including contact details for referral purposes (Appendix five - Government Facilities and Maternal Services offered). These details were provided to all participants. I also set aside some money to pay for transport or fees for any referral services that the mothers may have required. Despite this opportunity for referral and further counselling, none of the mothers used this opportunity. When asked about the reason for their declining referral, some alluded to having had some form of counseling after the loss of their babies whilst others felt that the support they had received from family members, spiritual leaders and friends during the time was sufficient.

7.5.1. Informed consent and language

The consent form contained an explanation of the study, its aims, potential risks, and benefits. The form also contained a clear statement that participation in the research was entirely voluntary and that women were free to refuse participation or withdraw from the study at any time, without negative consequences. The sample was obtained in Lusaka, within an urban setting, with a majority of mothers ably communicating in English and the remaining minority choosing to use a mixture of English and other two major languages, namely Nyanja and Bemba, with which the researcher is also fully conversant. All the mothers who participated could read and write English. The consent form was given to each mother to read and an opportunity to ask questions and seek clarifications was

given. After this, the participants were requested to provide written informed consent, out of their own free will, on the basis of the information given (Appendix Two- Information Sheet, Appendix Three- Informed Consent Form and Appendix Four - Informed Consent Form). Participants were given the option of either appending a signature or a thumb print, depending on their preference.

Although the consent form was in English, the interview was not limited to the English language and mothers were at liberty to mix these three languages in the course of the discussion of their experiences. The time required to participate in the study was solely dictated by the mothers. I tried to schedule meetings during times that were convenient to mothers and to help minimise any emotional risks or logistical burden to mothers. All the women contacted provided consent only after the research was explained. None of the participants' opted out during the process of the interview after signing the consent.

7.5.2. Confidentiality

Several measures were taken to ensure confidentiality. These included, giving mothers the choice to decide the time and venue for interviews, ensuring that each mother felt comfortable to be interviewed in spaces that were safe and private for them and in order to ensure anonymity, no names were written on any transcription or consent forms. Instead, each mother was allocated a number for the purpose of conducting the analysis. Furthermore, all raw data has been kept in a locked cabinet accessed by the researcher only. The plan is to keep the transcripts and tapes for a period of 5 years in order to facilitate possible publication and dissemination, after which, this information will be shredded and destroyed.

7.5.3. Cost / Payment

For all activities in this research study, the mothers incurred costs only with respect to their time taken to talk about their experiences. It was made very clear from the time of the initial engagement, before any consent was sought and as part of transparency, that there was no financial gain to be expected either for me as a researcher, or for them as respondents.

7.5.4. Inclusion and exclusion criteria

The study included all women, regardless of mode of delivery (Spontaneous Vaginal Delivery or Caesarean Section), who had experienced perinatal loss in a health facility in Lusaka. The study excluded women who delivered anywhere else apart from the health facility, those who felt uncomfortable to participate in the study and those below the age of 18 years.

7.6. Data collection

I collected data by using semi-structured, open-ended, face-to-face interviews, facilitated by a set of interview guide questions (Appendix 1 – Interview guide questions). These questions provided a framework to ensure similar information domains were sourced from all the mothers sampled. The guide thus assisted with generating data and encouraged mothers to disclose their thoughts and feelings related to their experiences. There was scope for flexibility in order to accommodate mothers who felt inclined to say a lot more on some aspects of the questions asked. In addition, participants' nonverbal behaviors, which served as indicators of thoughts and feelings, were also observed and noted (Creswell, 2009). The timeframe for the interviews was guided by the amount of information the mothers chose to share, including intermittent periods for emotional reactions. Generally, these interviews lasted between an hour to an

hour and half. This included going through the study explanation and the consent session.

7.6.1. Data management /analysis

In this study, mothers were given an opportunity to share experiences in their own words regarding their understanding of care received during pregnancy, from the time labour started, during delivery and up until they were discharged from the hospital. With the questionnaire as a guide, data was collected using tape recordings and these were then transcribed verbatim.

All the ten women's responses to questions asked were analyzed in order to identify emerging themes. Data analysis involved detailed scrutiny, analysis of recording content and analysis of each individual transcript. A process of repeated listening to interview recordings and reading of the transcribed interview data was undertaken line by line. This process facilitated colour coding of occuring patterns on transcribed narratives in order to identify categories which were further grouped into major themes. The study generated a large quantity of data that enabled the identification of similarities, differences and consistencies. These were further broken into smaller units as sub themes prior to final grouping into major themes. This process facilitated the identification of six (6) broad themes namely; following advice of friends and relatives, referral for specialist care, inadequate emergency care, neglectful and disrespectful care, poor communication and the need for psychosocial and emotional support.

These themes were collated and synchronized with identified research questions. I immersed myself in this inductive process in order to find the theory rather than approaching data with a theory (Seidel & John 1998). Consistent with the GT framework, analyzing data this way facilitated the process of theory emerging from the data as opposed to attempting to prove a theory.

8. RESULTS

This Chapter contains results following the process of analyzing information obtained from interviews with mothers who experienced perinatal loss in facilities of Lusaka. These results have been interpreted within Grounded Theory (GT) framework. The basic principles of grounded theory, is that theory is generated from data collected and theory is "grounded" in the data instead of being imposed on the data. This includes data generated from related subjects and studies (Creswell 1994).

Below is a table with a summary of broad themes and sub themes identified from the analysis.

8.1 Table 1

Broad themes	**Sub themes**
Following advice of relatives and friends	Listening to advice, advice on nursing and medical care, advice following previous care experience of relatives and friends, preparedness advice from relatives and friends
Referral for specialist care	Explaining ongoing care, inadequate birth preparedness, complications readiness, provider attitude
Inadequate emergency care	Inadequare complication readiness, inadequate birth preparedness, unavailability of essential drugs and equipment, busy nurses, few health providers,
Neglectful and disrespectful care	Negligence, client privacy, poor health provider attitude, inadequate care, busy with other women with live babies.
Poor communication	Poor provider attitude, communicating sad news, monitoring care, no information on general care, explaining ongoing care, ignorance on care bring provided
The need for psychosocial and emotional support	No counseling provided during and after demise of baby, respect for spiritual beliefs and mothers' religious faith, no support services offered.

8.2 Findings

8.2.1 Sample characteristics

Ten women were interviewed for the study. The ages of the women ranged from 24 to 46. Two out the ten women had no living children. Eight of the women were in some form of employment or running their own business and two out of the ten were unemployed, but living with employed husbands. They all appeared to fall in the bracket of middle socio- economical status. Of the ten, two of the women had been told that their babies had died of sepsis, three of the women had macerated stillbirths and five of the women's infants had birth asphyxia leading to death. All these mothers had a time lapse since these losses ranging from two months to twelve months.

8.2.2 Following advice of friends and relatives

During pregnancy, women become the centre of attention in homes, work places and communities. Hence, although already attending antenatal care services at a facility linked to Medical Insurance Scheme, once advised by family members to go to another facility for the birthing process, they tended to follow this alternative advice. The women narrated how they followed directly the advice given by friends and relatives without considering the implications on their health and their unborn baby's health outcome.

Participant 1: *Last year I started antenatal at private clinic Y, my sister and my aunt who previously delivered at hospital Z suggested that I also go to Hospital Z. So I went, I was quite big then and had a month to go.*

Participant 3: *My mum advised that hospital Z is the main hospital, when all these clinics have complicated cases they all rush to hospital Z. So it was better to go straight to hospital Z.*

8.2.3 Referral for specialist care

This study was conducted in an urban setting in Lusaka, Zambia, a city with a mixture of government and private health facilities within 5 -10 kilometer radius. As a result, women in the study had the option of choosing for antenatal care, any facility they were comfortable with or a facility that was conveniently located. However, although the women had these choices, when it came to delivery care, most ended up being referred by a Doctor, Nurse or Clinical Officer to deliver at government hospital Z in Lusaka, according to the risk identified. The women reported that they knew that most of the specialist doctors working in the private hospitals and clinics were also working in the same government hospital Z. They worked in private institutions to earn extra money. Most mothers who have medical insurance or are able to pay for private institutional care would rather go to private hospitals or clinics as they perceived that these institutions allow mothers a greater sense of autonomy over choices of care. However, it was noted that when a risk or a complication was identified, these private institutions did not have the capacity to deal with some of these emergencies due to inadequate equipment and specialized personnel for neonatal care facilities. As a result, mothers would then be referred for transfer to specialized government hospital for this purpose. During this period, the mother's major concern would be the life of her baby as narrated below:

Participant 3*: We all rush to government hospital Z because we know that's where the best doctors are found despite the nursing care being different from the care in private clinics.*

Participant 6: *Being the first pregnancy, it was better to go straight to the referral hospital Z instead of waiting for complications*.

When labour pains commenced, three participants, despite going to their usual health facilities, were redirected to the referral hospital because they were

assessed to need specialised obstetric care. There had been no prior warning by health staff of complications during the antenatal period and hence this created significant anxiety for the mothers.

Participant 4*: When labour pains started, I went to the clinic only to be told that I could not deliver from the facility because of the previous caesarean section. So I had to go the government hospital Z to deliver.*

Participant 5: *At the clinic they tested my urine. Then they told me there was protein in the urine and my blood pressure was raised so I needed to be referred to hospital Z.*

From the participants' narration, there was no indication that the reasons for referrals were explained and it appears there was no attempt by staff to allay any maternal anxieties during these urgent referrals for specialized care.

8.2.4 Inadequate emergency care

It was the general impression among these women that once admitted in the health facility, whether private or government, there was no perceived urgency with regard to staff obtaining and administering emergency drugs, equipment and general nursing care. Some of the mothers were told by staff about the shortages of human resources and unavailability of some essential drugs in these facilities. Other mothers further observed that the health providers appeared busy taking people to operating theatres, admitting other mothers and placing them in their rooms and writing reports. Some even experienced calling for help and not receiving any attention because, the health providers carried on with other health related business.

Participant 5*: They didn't check on me or even the blood pressure the whole night until four am, when I felt severe pains and I rang my husband to come to the hospital from home.*

One baby was referred to government hospital Z because of a deteriorating condition and a lack of appropriate medication at the private hospital did not have the drug that could revive the baby. At the government hospital. At the government hospital, the baby died later on in the day and the diagnosis was cord strangulation at birth. This mother stated in between sobs:

After the burial, I was so hurt and I knew all this happened because of negligence as there was not enough care.

8.2.5 Neglectful and disrespectful care

Mothers interviewed described having experienced some form of maltreatment and feeling disrespected whilst in the health care facilities. One mother who had a difficult delivery in the night, and had her baby placed in the incubator, asked if she could have a bath in the morning. She was permitted to go to the bathroom unaccompanied. In the process of bathing, she said she felt dizzy, lost consciousness and hit her head. It was only after the nurses heard the bang in the bathroom, that she was picked up and assisted back to her bed and later given some painkillers when she complained of a headache.

Another mother admitted to the facility with a known stillborn was advised to wait on the ward for labour to commence or wait for a turn to go to the operating theatre. She was told by health providers that her condition was not on the priority list because the baby was already dead. This mother felt very devastated because she was admitted to the same ward as mothers who were waiting to deliver to live babies. She stated that she would have preferred to have been discharged to go home and wait for nature to take its course from there.

Most of the mothers indicated they had been neglected physically and emotionally. This was observed because the nurses were not checking any vital

signs from the time of admission until after many hours later. One of the mothers had to call her husband using her mobile phone to alert him that she was not being attended to. It was only after the husband came to the ward and started complaining that the nurses started to pay attention to her.

Participant 5: *My mum went to tell the nurses that I was throwing up…… the nurses just looked at her and ignored.*

One of the mothers had been told that there was no fetal heart detected during the time of admission and that the staff could do nothing to help as the baby had already died in utero. She narrated being given a drug to acclerated contractions and help expel the baby. When the baby came out it was indeed dead and she delivered completely alone.

Participant 10: *I asked if I could go to the toilet and the nurse told me to go back to my bed. The nurse delayed coming and I felt the urge to open bowels just on the bed. …….. So when I opened my legs the baby came out……. I shouted for the nurse, but no one answered. So I just lay there and I knew the baby was dead. (In-between sobs)*

8.2.6 Poor communication

The study revealed skills gaps with communicating progress of care including breaking bad news to mothers and their families. Some mothers indicated not receiving clear explanations on procedures being performed on them and their babies. They felt it was important for health providers to keep mothers informed regarding the progress and care of the babies. Most of the mothers felt that news of the death of their baby was not conveyed in an empathetic manner nor was the cause of death fully or clearly explained.

It was observed by mothers that nurses and doctors seemed in a hurry to continue with their usual work of attending to the next client or mother. Other

mothers felt providers blamed them for the deaths by insinuating that if they had come on time, the baby would have survived. Consequently, most of these mothers felt reprimanded, judged and blamed for the circumstances leading to the loss. They felt news of the loss should have been communicated in the presence of either parents or a supportive person. Furthermore, most mothers felt that nurses and doctors used difficult medical jargon to describe the conditions and problems encountered in the process of care when communicating the loss. These mothers would have appreciated explanations in simple language including granting them time to ask questions. Explanations, when given were provided very quickly and hurriedly as health staff continued with other work.

***Participant 10**: I do not know whether it's the medicine which killed the baby or something else, because when they inserted the syringe I felt hot.*

***Participant 4**: I do not know why and whether the baby's condition had changed for the worst because they were not explaining things properly. And everything was so new to me being a first time mum. I didn't know anything.*

As mothers narrated their stories, a sense of anger and hostility directed at health care workers and a sense of self blame was noticeable. It was not uncommon for participants to sob and sniff during the interview process. I had to ask some of these mothers if they wanted to continue or whether to defer to some other time or day. However, they all appeared eager to continue and instead asked for a few minutes to calm down and compose themselves before continuing narrating their experiences.

***Participant 1:** I requested to have an ultrasound … but they told me it's was not necessary. Maybe if they had just done it they would have saved the baby. (Tears running down and sniffing sounds being heard).*

***Participant 2**: I went there with my husband and found they had covered him up. It was not nice. (Crying and sniffing)*

***Participant 6**: They told me 'if we cannot maintain your blood pressure we will just have to terminate your pregnancy'……the doctor did not really explain as he just said it was better to save my life than that of the baby.*

Mothers were asked how best, in their own opinion; bad news including worsening of mothers' condition ought to be conveyed. Some suggestions emerged:

***Participant 2**: Medical people should communicate with people, counselling them, talking to patients and telling them that they are trying to do their best. They need to provide not just a social counsellor but even a spiritual counsellor.*

***Participant 1**: A doctor should not only come when something is wrong, leaving everything to nurses.*

***Participant 3**: Health workers need to put everything in black and white, informing clients at every stage instead of just overhearing things.*

It appears that most of the mothers were not aware before labour about any risks in their obstetrical history nor were they advised on actions to be taken once labour commenced. The women also mentioned that health care providers did not say anything about counselling or postnatal review after the loss of the baby.

***Participant 4**: I was just overhearing that the condition of the baby was not that good. I would have appreciated it more if they had been straight with me.*

8.2.7 The need for psychosocial and emotional support

Some mothers indicated finding comfort and support as they related and socialised with other mothers who had also lost babies, on same the ward. Others appreciated the presence of their spouses, relatives, spiritual leaders and friends. The period immediately after the demise and shortly after being discharged from the facility appeared to have been critical points at which these mothers needed substantial emotional and psychosocial support.

Participant 8*: He stopped breathing and they still kept the body in an incubator so that I could see him. When I got there I was still in a state of shock so I couldn't cry because I couldn't believe what happened and I was all alone".*

Participant 3*: I feel the best counselling is spiritual and I believe God is the best comforter.*

Mothers revealed that men and women differ in the way they responded to perinatal loss.

Participant 2*: My husband tried to be strong for me, but he was hurting and after a few months he broke down, he couldn't take it anymore.*

Participant 10: *My husband like other men may want to come out strong. However, I have noticed that it's really affecting him because he has even lost his appetite and his has lost weight.*

Despite indications of some mothers not receiving insufficient support, a few mothers did feel supported and cared for after the demise of their baby.

Participant 3: *I never really spoke to anyone but just a workmate and friend. We were there for each and talked and discussed. It helped a lot, because I had someone who had gone through a similar situation.*

***Participant 5**: The only community that gave me some kind of support was my work place because these people knew me…….they heard about the loss……. Some women brought me books to read because they knew it was not that easy.*

Although many participants mentioned inadequate support and care from most professional health workers, a few mothers mentioned that some nurses were "nice" and sympathetic and that they tried to explain matters relating to the perinatal loss.

***Participant 2**: The nurses were good they would check on me and made me feel at ease and ask questions.*

***Participant 5:** They didn't counsel me, except one of the nurses who was really nice to me.*

Spiritual beliefs and encouraging words from the Holy Scriptures were of value to some of these mothers. With the belief that their loss was part of God's will for their lives, the mothers were more easily able to come to terms with it. Furthermore, these mothers felt that respecting people's spirituality and making spiritual counselling available, would have benefitted those who have religious faith.

***Participant 9:** I would strengthen other women to place all these issues in the hands of God…… One needs to be very prayerful. God knows whatever will come my way.*

***Participant 8**: There was no counselling, the only sort of counselling I got was from my previous clinic. That's where I saw one of the doctors there who knew me and was able to talk to me and encourage me. This helped including family, friends, prayers and my faith in God has helped the healing process.*

9 DISCUSSION

9.1 Introduction

This chapter discusses the results presented in the previous chapter. The discussion will integrate relevant similar research findings and compare these with the findings of this study in order to answer the original research questions. Information has been gathered in order to answer two basic research questions, namely:

1. How did mothers, delivering in a health facility, perceive health and supportive care after perinatal loss?

2. What support needs and services did mothers experience immediately after the loss of baby, during their stay in hospital up until discharge from the health facility?

The Grounded Theory framework provided a means to develop theories that are grounded in the data obtained (Benoliel 1996, Strauss & Corbin 1990). In this discussion the words "mother/ mothers" and "woman/women" are used interchangeably.

9.2 Following advice from friends and relatives

Generally and traditionally, Zambian culture encompasses a lot of extended family ties. Family members gather together around marriage, sickness, childbirth and death. Family discussions are held during this time and family members keenly listen and keep family values intact (Maimbolwa 2004).

In particular, child bearing, child birth and child rearing are very important components of African family life. These life stages bring to bear varying cultural values, beliefs and traditional experiences (Ngomane & Mulaudzi 2010, Phoenix

& Woollett 1991, van Balen & Bos 2004). In traditional African society, pregnancy often brings joy to the matrimonial home and the entire extended family as it constitutes an achievement (Ngomane & Mulaudzi 2010). This achievement is profoundly influenced by cultural beliefs and traditions associated with childbearing. This is further influenced by the way individual societies view and manage childbirth beliefs, practices, and values associated with reproductive health and the role and status of women (Callister 1995, Lauderdale 2003).

In traditional African societies, once the pregnancy becomes conspicuous, the woman becomes the center of attention in the family, the neighborhood and among friends. In the process women, are bombarded with pregnancy and childbirth advice which they trustfully accept even though transmitted with a mixture of myths and superstitions (Collings et al. 2002, Maimbolwa 2004).

From the present study, it appears that adhering to advice from non health professional led to poor identification of pregnancy danger signs which eventually led to adverse health outcomes. Mothers in the study narrated several experiences of obtaining advice from friends and relatives and willingly complied with this advice, despite having had previous consistent antenatal nursing care elsewhere. There seems to be a great disparity between the advice given by relatives and friends, and that given by health providers. It is further observed that mothers, even with first uncomplicated pregnancy experiences, denied themselves opportunities of continuity of care with their constant antenatal clinic because they adhered to advice given by relatives and friends to attend care elsewhere.

This behavior therefore indicates the need to include family and community level participation in health care. Over 60 percent of women in Zambia do not take part in decision making in their homes (CSO, 2001-2002). It is for such reasons that the Ministry of Health (MoH) in Zambia, working with other strategic partners in the 2012-2013 piloted an initiative known as Saving Mothers, Giving

Life (SMGL) that included community participation in order to reduce maternal newborn mortality. This initiative involved a public-private partnership and encompassed a wide scope of activities that included mobilizing community health workers and traditional birth attendants training them to become Safe Motherhood Action Group (SMAG) members. Their role was to raise awareness in the communities of danger signs of pregnancy, of the need for community leaders and champion leaders to influence their people and to create demand for mothers to deliver in health facilities (Kruk et al. 2013).

Mothers' behavior may also indicate that being informed of facts during antenatal care may not determine women's choices. Rather it may be the style of information transfer that determines consequent behavior. Interestingly, the mothers in the study were all residing in the urban setting with easy geographical access to health facilities and health providers. However, it was clear in the study that mothers trusted family members and friends more than health workers. This is because they did not seem to consider continuity of care in their usual facilities to be beneficial and easily changed health care facilities upon receiving advise from family and friends. If the research was undertaken in rural and remote areas where facilities were inaccessible, other delay issues would have probably emerged.

9.3 Referral for specialist care

During the antenatal period, some maternal complications such as multiple pregnancy, breech presentation and previous caesarean section can be addressed timeously in order for appropriate referral to be made to the next level of care, before labor commences. The policy in Zambia requires that pregnant mothers attend the nearest government health facility for health care. This has arisen in order to realize the vision of bringing health care as close to family as possible (NHSP, 2011 – 2015). However, in the event that a patient needs specialised care at a secondary level facility, the primary health facility is obligated to provide a referral note with a summary of the patient's care issues requiring attention. The

facilities are advised not to attend to a patient without a referral note unless they choose to be admitted to a fee paying ward. This is because it is anticipated that a sick mother or newborn will be referred from one level of care to the next in a much more stabilized form, giving both the mother and the baby greater chance of survival (CSO 2007).

Consequently, when labor commenced, most of the mothers in the study went to the usual clinics they had been attending for antenatal care and others went to the facilities they had been advised to attend by relatives and friends. The three mothers referred for specialised care had not presented with any obstetrical risk during the antenatal period. The mothers narrated that the process of being referred to another facility increased their levels of anxiety as the condition of their pregnancy was not explained fully. Despite the common use of mobile phones and the availability of various network providers in the study, there was no mention of the health providers making referral arrangements by phones.

The situation is worse in the rural and remote areas of Zambia where access to the nearest health facility is a challenge because of long distances and impassable roads, especially in the rainy season. Furthermore, many places have no mobile network connectivity, making it difficult to call for an ambulance in time of emergency. Although the women in the study lived in an urban environment, they too experienced delays in reaching health facilities and accessing care. The women were affected by delays incurred when significent time was lost due to moving from one facility to another and trying to find their own means of transportation, resulting in increased delay of receiving appropriate clinical care at the facility (Thaddeus & Maine 1994). It was therefore noted that, there appeared to be an absence of a triage system that would have enhanced prompt referrals to the next level of care.

9.4 Inadequate Emergency Obstetric Newborn Care (EmONC)

Every pregnancy has a potential risk of developing into a life-threatening obstetric complication that would require prompt emergency obstetric care (EmONC) services (WHO 2000). Global evidence indicates support for a full continuum of care from community to health facilities with adequate skilled birth attendants providing quality services that build community trust in the health system (Gabrysch et al. 2011, Koblinsky et al. 2011, WHO 2012).

In developing countries, maternal and child mortalities remain high and yet it is every woman's right to receive quality health care services (Bhutta et al. 2010, United Nations Population Fund 2011). Hence, midwives and medical professionals with midwifery competencies form an important part of the skilled workforce as they are expected to provide routine care during uneventful deliveries, identify and manage complications of childbirth before they become life threatening. There is a general assumption that hospital settings are structured to provide a safe environment for mothers and babies during childbirth (Fugita 2011).

This was not the experience and perception of the women in the present study. Once referred or admitted to various health facilities, most of the mothers felt that whatever was perceived as urgent from their viewpoint was not perceived as such by health providers as observed from the actions of health providers. When some mothers called for help, some health providers bluntly told the mothers that they were short staffed. Some further observed that the health providers appeared occupied with other health related issues including taking people to operating theatres, admissions, and writing reports.

Global interest is building momentum towards accelerating activities to reduce maternal and child mortality rates. Interventions based on a combination of potentially effective approaches that have been proven to enhance performance among health-care professionals to be clinically-oriented are being scaled up

(Lawn et al. 2006, UNICEF 2006). Interventions such as Helping Birth Breath Techniques (HBB) evidenced by research studies that have indicated that most babies die as a result of asphyxia at birth and resusitating skills in health providers can prevent this from happening. Kangaroo Baby Care (KMC) that encourages bonding and skin to skin contact between mother and baby to enhance optimum warmth for the baby (Lawn et al 2006, UNICEF 2006), and Essential New Born Care (EmONC) clinical mentorship activities targetting health professionals to improve the quality of obstetric care and to prevent adverse maternal and neonatal outcomes. Others are evidence-based outreach social mobilisation activities that integrating community involvement to developing opinion leaders, strengthen community action groups, reinforce maternal neonatal reviews and surveillance systems at facility and community level (Flodgen et al. 2011, Jamtvedt et al. 2006, O'Brian et al. 2007, Van Lonkhuijzen et al. 2010).

Globally, one in three pregnant women gives birth without a midwife or a skilled birth attendant (WHO 2012). In many low income countries rates of unattended births are much higher. For example, in the Zambia, 47 percent of births have no midwife or skilled health worker present compared to only 1 percent of women in the UK give birth without a midwife or skilled birth attendant (CSO 2007, Save the Children Fund 2011).The few available skilled health providers have to grapple with management of mothers, neonates and perinatal deaths which are potentially on the increase having implication on their nursing practise.

The ultimate desired goal for these activities and strategies are to have every birth attended to by a midwife or a skilled birth attendant. This is a far cry to the reality faced by many of the women in this study, where their care took place in under-staffed and over-stretched health service areas, where health workers had multiple roles and a likelihood of competing demands impacting negatively on quality health delivery.

9.5 Neglectful and disrespectful maternity care

Neglect, disrespect and abuse in maternity care are violations of human rights that are fundamental entitlements due to all people. These rights have been enshrined in international declarations and conventions (Bowser & Hill 2010). Neglect, disrespect and abuse in facility based childbirth have been identified as critical barriers impacting the utilisation of skilled birth care. This constitutes a common cause of suffering and human rights violations for women in many countries (Fugita et al. 2011). Locally, research has not studied neglect, disrespect and abuse on the maternity ward comprehensively, however in Tazania, a study demonstrated poor treatment of clients as an important factor in health care decision making. This included decision regarding where to seek care and whether to seek alternate sources of care or none at all (Kruk et al 2009). Globally major categories of neglect, disrespect and abuse have been identified namely; physical abuse, non-consented care, non-confidential care, non-dignified care, discrimination based on specific patient attributes abandonment of care, and detention in facilities (Bowser & Hill 2010, Jewkes et al. 1998). These have been known to constitute important barriers to accessing quality of care which are directly related to poor clinical care and patient dissatisfaction (Fugita et al. 2011, Goer 2010).

Mothers in the study narrated several examples similar to identified global categories of disrespect and abuse to women in the course of delivery. For example, nurses were seen to be busy with other mothers who had live children and those who were yet to deliver, abandoning those with stillbirths. It was difficult in the study to state whether it was because the nurses did not feel confident enough to comfort bereaved mothers or whether they did not know how to engage with the mothers in fear of being misunderstood or whether they were experiencing compassion fatigue or burnout due to work overload. As the study did not incorporate the health providers' views, this remains unclear. Nonetheless, from mothers' observations and perceptions, they concluded that

they were left unattended after admission because nurses were overwhelmed with work and short staffed.

9.6 Poor Communication

Good health worker patient communication has been linked to increased patient satisfaction and patient adherence to medication and treatment regimens as well as to improved clinical outcomes (McCabe 2004). This process comes with primary interpersonal skills such as good listening, explaining things well, being cheerful and friendly. The mentioned qualities have been found to be of vital importance to facilitating interactions that determine the development of a caring relationship (Fraser 1999).

Most women in the present study had negative perceptions of health provider communication. They described nurses and medical personnel giving scanty information, being preoccupied with other duties and handing over shifts to nurse colleagues so that they go off duty. This underscores how understaffing pressurises a few health providers who carry the bulk of work, and results in inadequate health provider communication.

Perinatal loss is a painful form of bereavement, which conveys feelings of helplessness, placing bereaved parents in vulnerable positions that need care, support, sensitive handling and careful communication (Chambers & Chan 2000, Gaze 2000, Hughes et al. 1999). For that reason, communication between health workers and mothers should not function merely for the transmission of information, but also for the transmission of feelings, recognising the feelings of mothers and letting them know that these are acknowledged and validated (Attree 2001, Sheppard 1993, Thorsteinsson 2002, Wilkinson 1999). Poor communication has been attributed to staff attitudes, low work morale, stress, fatigue and interruptions such as shift changes. Other predisposing factors have included issues of hierarchy, power relationships, difference in training, time

pressures, workload, lack of organisational policies, protocols and organisational culture (Jarrett & Payne 2000).

Another interesting factor revealed by mothers in the present study had to do with the language and terminologies used in communicating. Mothers revealed that health providers communicating progress about the baby was generally not clear as they used a lot medical and nursing terminology with which mothers were unfamiliar. In addition, this was being communicated hurriedly, thus not giving mothers opportunities for clarifications, comments and suggestions. Mothers further noted that health providers appeared to be more concerned with "getting on with their work" and attending to new clients with live babies as opposed to attending to them, thus portraying uncaring behavior to these mothers who had lost babies.

A patient – centered approach focusing on patient interest, welfare, care and support ought to be central in nursing and medical care as this eventually leads to improved patient satisfaction, adherence to treatment and patient health (McCabe & Timms 2006, McCabe 2004). Other researchers have stated that patient-centered communication does not take up more of the nurses' time or require extra resources (Astedt-Kurki & Haggman-Laitila 1992, Williams 1998). However, nurses may not have adequate communication skills due inadequate capacity and training, placing them in a difficult position when confronted with unanticipated medical events involving clients in their care (McCabe 2004).

It is clear that communication becomes a critical component in these relationships and that it largely depends on the nurse's ability to listen, assimilate, interpret, discriminate, gather, share and handover critical information professionally (Manning 2006). For this reason, the importance of good communication skills in professional training and education need to be emphasised (Tongue et al. 2005).

9.7 Need for psychological and emotional support

The provision of psychological and emotional support has been highlighted as a necessary intervention out of concern following a perinatal death in a number of literatures including Cochrane review (Bartellas and Van Aerde 2003, Chambers and Chan 2005, Lasker and Toedter 2000, Toedter et al. 2001, Janssen 1997). Although Chambers and Chan in the Cochrane review, did not find conclusive evidence to support the effectiveness of interventions done to bereaved group. Nonetheless, other researchers in other studies indicated that a small percentage of women are at greater risk of developing depression, anxiety and other grief complication following a perinatal death (Bartellas and Van Aerde 2003, Lasker and Toedter 2000, Toedter et al. 2001, Janssen et al. 1997).

In most developed countries, skilled health providers are present at 99 percent of births offering a unique opportunity for providing physical and emotional support to women in labour (Adam & Bianchi, 2008). It is within these same environments that reduced perinatal mortality levels are observed and documented (Lawn et al. 2005) including evidence based strategies and support services in the event of a negative birth outcome (RCOG 2008). In contrast, low resource regions, with larger proportion of deliveries, are still lagging behind with inadequate skilled personnel attending to deliveries rising from 55 per cent in 1990 to 66 per cent in 2011(MDGs, 2013). Women continue to deliver alone or with inadequate skilled care, as low as 50 per cent in Southern Asia and sub-Saharan Africa and impacting negatively on maternal and perinatal health outcome (MDGs 2013).

Perinatal loss may represent an awaited birth becoming a death or a brief life that is extinguished with all its anticipated hope and promises (Raphael 2009). It becomes a unique grieving situation for the mother and in some case the father. Research into emotional processes of bereavement follows a well-defined normal grief pattern namely; a sense of unreality, disbelief and numbness giving way to intense grief, unwarranted grief, self-blame followed by irritability and anger

towards others or towards the deceased for dying (Raphael 2009). It has been discovered that most mothers will have intense memories of their baby's death including events surrounding it (Cole 2012, Raphael 2009).

Hence, support given to a mother immediately after a loss in a facility becomes relevant. Additionally, empathy and care mothers receive at the health facility greatly impacts on their memories of their child (Raphael 2009). Unless medication to stop lactation is given early after the loss of a baby, women may be additionally distressed by the lost opportunity to breastfeed and nurture a baby as they naturally commence lactation with subsequent breast engorgement (Cole 2012, Raphael 2009). Apart from this physiological experience, some mothers immediately after a perinatal loss develop a general sense of anxiety, insecurity, uncertainty, doubt and concern that the loss of another child may occur (Cote-Arsenault & Marshall 2003, Lamb 2002, Raphael 2009).

Almost all of the women on the study did not receive any emotional and psychosocial support or words of sympathy from health providers after experiencing the loss of their babies. Several mothers cited health providers blaming them for coming to the facility late. Further, most of the nurses appeared busy, continuing to focus on other women who were pregnant and seemingly forgot about those who had lost babies. The news of the perinatal loss was not communicated caringly because some of the mothers were alone when the news was relayed to them. For some women, this resulted in overwhelming and intense feelings of anguish, guilt and many struggled with unanswered questions. These women felt these feelings would have been ameliorated had there been some kind of emotional and psychological support provided by health care staff.

Most of the health facilities in Lusaka providing maternity care have an influx of mothers for delivery that surpasses the bed capacity at these facilities. So at the time of admission, some mothers are asked to wait on benches or even to lie

down on the floor until labour is established. Therefore, in some of these facilities, mothers who have lost babies are then asked to share beds while they recuperate after delivery. These are common scenarios in most government hospitals and tend to be accepted by mothers as they would have no choice at this stage From this study, it appears that it is at this time that mothers start to share their personal experiences with each other. For some mothers, this experience became a source of comfort as they were able to share with each other their personal experiences of loss. It made them feel they were not alone going through that kind of a loss.

Mothers, who were religious, drew on their spirituality and faith in God as an important exercise to understand and cope with their loss. These women dealt with their losses differently and for some a sense of meaning was obtained through interpreting the demise as being within the plan of God. Four of the mothers appreciated being visited by their spiritual leaders at home after the demise of their babies. However, the opposite may be experienced by those who lack religious affiliation resulting in mothers gaining little spiritual support from this direction (Lovell 2001). Conversely, it should be noted that perinatal loss may also cause the affected parents to turn away from previously held religious beliefs due to embitterment and questioning why God allowed the situation (Marrone 1999, Van & Meleis 2003, Lomas 2004). Nevertheless, while some bereaved parents may reject their religious beliefs, others may find their beliefs strengthened by the experience (Cait 2004, Tedeschi & Calhoun 2004). This was noted from the experience of the mothers in the study.

None of the participants was offered counselling or psychosocial support services immediately or prior to discharge. Some of the mothers who had been referred from the first level of care and from private clinics used their initiative and went to see their obstetricians to discuss the events. While others discussed with friends and relatives who were nurses to understand the events and others had their spiritual leaders who continued to encourage them in the faith. Those who

had gone to see their obstetricians from the referring facilities were able to discuss what could have gone wrong and also talked about the need to recuperate before thinking of conceiving again. One woman, who had lost her very first child, was still questioning during the interview as to whether she will be able to conceive and have a normal pregnancy. This suggested the need for supportive and follow up services for these mothers as the grieving process projects over a period of time.

9.8 Discussion summary

This discussion has shed light on weaknesses in clinical practice, the quality of nursing care, health care systems, and supportive services. These flaws negatively impact the psychosocial and emotional wellbeing of mothers experiencing a perinatal loss at a health facility. Research has also often concentrated on pathological and physical aspects related to pregnancy, childbirth and the postpartum period.

Health is a fundamental human right, encompassing access to quality health services (CSO et al 2009). The health of the mother and her newly born baby have always been areas of interest and concern in many cultural and traditional groups in Africa. This can be seen through various traditional practices around the time of delivery and soon after childbirth (Pearce, 2000). This may, in part, be attributed to gender issues. Gender inequalities in Zambia have been recognised as important causes of inequality in health care and are an important determinant of health (UNDP 2011). Women's social status and gender norms play a major role in their health. For example, although women play a decisive role in daily domestic life at home, the husband usually makes decisions in matters of reproduction (CSO 2009). Some studies have revealed that early and prompt access to care service during pregnancy is usually dictated by traditional and cultural beliefs valued by the mother, partner, family and general community (Maimbolwa et al. 2003, Mathole et al. 2004, Mpembeni et al. 2007).

In Zambia, psychological distress during the pergnancy and the perinatal period usually goes unnoticed and unreported. This is perpetuated by the absence of a deliberate health policy focusing on screening and management for depression during antenatal and postnatal visits (Maimbolwa 2004, Mwape et al. 2012). This has been further worsened by human resource shortages giving rise to critical shortages of midwives in labour wards (CSO 2009). A report by the UNDP estimated that Zambia would need to double the current number of midwives to achieve the MDG 5 target of 95% of births assisted by skilled and motivated birth attendants (UNDP 2011). This existing health resource gap negatively impacts skilled birth attendants' competencies to manage the increasing numbers of pregnancies, the subsequent number of births and births associated obstetric complications. Until policies are implemented to address the human resource crisis, this scenario will continue, with negative impacts for maternal and new-born health and women's emotional wellbeing (UNFPA 2011, World Bank 2011).

10. STRENGTHS AND LIMITATIONS OF THE STUDY

Strength of this study is that the chosen methodology enabled an in-depth exploration of bereaved mothers' perceptions of care and support.

My role as researcher, a nurse by profession, with previous personal experience of a perinatal loss was a strength in itself. I was able to gain the confidence of these mothers upon introducing myself. Whilst this may have been advantageous, I was aware of the possibility of being subjective and not totally objective in the collection and processing of data collected.

Although the results of this study provided many new insights into perinatal bereavement, some limitations were noted. One limitation is the time factor; the mothers relied on memory to recall their experiences, feelings and attitudes regarding their bereavements. The time lapse ranged from two to twelve months. Another limitation of the study is that the majority of participants were married at the time of loss, which probably influenced their experiences and perception of care and support because they all reported that their partners were supportive. An additional limitation was the exclusion of men and specifically expectant fathers. This would have provided additional information regarding men's perceptions of care rendered to their partners in child birth subsequent to the loss as well as paternal experiences and support needs. Another limitation was that due to logistical constraints, it was not possible to interview the attending health workers. This would have provided a useful opportunity for triangulation of data.

11. RECOMMENDATIONS

The findings of this study challenge current health care and nursing practice for mothers experiencing a perinatal loss in a health facility. Service gaps experienced by these mothers highlight the need to recommend appropriate and user-friendly strategies that will enhance psychosocial support services for mothers and their families in Zambia. Below are recommendations for various levels of care:

11.1 Community and family involvement and particpation.

11.1.1 Strengthen the use of Safe Motherhood Action Groups (SMAGs) by incorporating the use of a birth companion

Mothers in the study consistently attended antenatal care within their geographical areas prior to delivery. However, the study revealed that mothers made decisions regarding where to delivery following advice from family and friends. This underscores the need to strengthen the use of existing community volunteers known as SMAGS. This action group in Zambia consists of Traditional Birth Attendants (TBAs), Neighborhood Health Committee (NHC) members and community members who have been given skills to advocate for safe motherhood, birth preparedness, and complication readiness at community level. SMAG members are selected by community members who are well-respected, honored and valued within their communities. These groups are mostly found in rural areas of Zambia because of the increased prevalence of maternal, neonatal and perinatal mortalities. SMAG members accompany mothers to the facility to make sure that no problems are encountered on the way. They exert a significant influence over maternal health issues at community level. This group in the community is a strategically placed to integrate traditional and cultural issues in maternal health care.

The study recommends SMAGs be established in every district in Zambia with a view to incorporate volunteer management and coordinating system with

equitable remuneration, supervisory, and accountability mechanisms in place. Zambia is still in the process of finalizing a community volunteer policy, hence, this component could be considered for integration.

Women's health is determined by the environmental, social and economic circumstances in which they live, and these are key elements to reducing gender health related inequities(UNDP 2011). Therefore, SMAG male members are better placed to advocate for male involvement and address gender stereotyping issues that impact negatively on the pregnant mother and the unborn baby. These men are strategically placed to be primary change agents in the process of influencing positive gender-equitable attitudes and behaviors associated with better maternal health outcomes and less violence against women.

11.2 Use of mobile technology in health (mHealth)

In order to address referral delays and to improve information sharing between mothers and health providers, the use of mobile technologies, such as cell phones, provide an opportunity for real-time health information exchange. The benefits and consequences (intended and unintended) of using Mobile Health technologies remain uncertain. mHealth has been known to strengthen tracking of patients through referral systems, to improve the dissemination of up-to-date dosage information and health records, and to expand community access to health information hotlines (Labrique et al. 2013). These applications have helped patients manage their treatments when attention from health workers is costly, unavailable, or difficult to obtain regularly. For example, in Kenya, a project providing Short Message Sending (SMS) SMS-based messaging to monitor and support antiretroviral (ARV) therapy estimated to have raised ARV patients' adherence to their treatment regimens by a quarter (Lester 2010). In Zambia, the Saving Mothers Give life (SMGL) project, which started as a pilot in late 2011, used mHealth to strengthen maternal service access and referral systems used by pregnant mothers during the antenatal, delivery and postnatal period via a triage

system that integrated community members and health providers. The preliminary results have indicated the feasibility of using a combination of mobile text message reminders and community based volunteers to increase focused antenatal care attendance by pregnant women in rural settings of Kalomo District in the Southern Province of Zambia (Kruk et al 2013). Therefore, replicating such mobile-based interventions that fit into one or more of the three delays models may contribute to the overall strategy of overcoming barriers to care. This will further contribute to health knowledge, behavior change communication, delivery of care and ultimately improve health outcomes. This will further enhance and promote Public Private Partnerships with various network providers in the country and lead to higher levels of efficiency in service delivery, supervision, and management practices.

11.3 Establishing religious / community support groups

In this study, a number of mothers mentioned the benefit received from talking with their spiritual leaders who comforted them with the word of God when they experienced the death of their babies. None of these mothers had an opportunity to meet with any hospital-designated chaplain or social workers for the purpose of receiving emotional and spiritual support. Therefore, it is clear that this is a huge gap in the care of women in need of spiritual support immediately after the loss.

This is an area to explore at community level for consensus building among community members, professional and church leaders regarding establishing support groups that can work closely with health facilities. Literature review and lessons learnt from similar groups internationally suggest that the establishment of such support groups have resulted in significant benefit to bereaved families (Cote-Arsenault & Freije 2004, Honikman 2000). These support groups in their discussions have included elements such as: stages of grief, misconceptions about grief, grieving differences in men and women, helping siblings grieve, life after perinatal loss, reactions of friends, reasons for pregnancy and infant loss,

subsequent pregnancy and creating remembrance (Cote-Arsenault & Freije 2004, Honikman 2000). Other groups have organised themselves and formed networks with home based groups, community based organizations for skills building. Stronger partnerships have been built in the process that are contributing to reducing maternal and neonatal mortality and morbidity (Honikman 2000, Rosato et al 2010)

Similarly, support groups can comprise people in comparable situations or have been in related situations. This way, the group facilitates empathetic sharing of experiences and offering support to one another. These groups can also work closely with health workers to facilitate other activities of interest to the group such as conducting of verbal autopsy at community level. Capacity building on conducting these processes can be given to this group so that whenever a death occurs in a facility or community, there is mutual accountability between communities and health workers.

11.4 Enhancing professional health provider performance

Global evidence has demonstrated that skilled health providers are an important workforce impacting health care outcomes (Chen et al 2004). The human resource crisis in Zambia is a major obstacle to the provision of quality maternal newborn healthcare services and to the achievement of the national health objectives and MDGs (UNDP 2011). This could be attributed to various factors including insufficient finances to recuit and deploy additional staff, inequitable distribution and inadequate capacities to perform required tasks. Findings from the current research study support this. The following are recommendations to address these challenges:

11.4.1. Increasing numbers of skilled health providers

Addressing the human resource crisis will require concerted efforts to address student nurse training, recruitment, retention and distribution. Zambia is currently experiencing the mushrooming of private nursing training schools

alongside government and mission-initiated training institutions (NHSP 2011 - 2015). This opportunity requires government and regulatory statutory bodies in Zambia to cultivate a keen interest in regulating and conducting quality control of such schools with the objective of enhancing quality education and performance. Furthermore, the Zambian government has been soliciting donor investments in developing training infrastructure and supporting the expansion of intakes for student nurses and allied health staff (UNFPA 2012, DFID 2012). While this is a good initiative on the part of government, ensuring that commitments of this nature are appropriate and sustainable is paramount. Government needs to ascertain that donors are flexible enough to co-invest in human capital through supporting payment of viable salaries for nursing and midwifery practice. One such example is the implementation of performance based financing (PBF) that includes establishment of incentive systems to reward facilities, health workers, and district health administrations for improved outputs and outcomes. This is currently being in implemented using funds from World Bank in Ethiopia, Rwanda, Tanzania, Zimbabwe and Zambia (World Bank 2013).

11.4.2. Improving health provider performance

Despite the desire to have a well-capacitated workforce, it should also be noted that, many in-service workshops and training programmes are inequitably distributed among nurses, may end up taking staff away from their jobs and work stations for excessive periods of time, causing resentment and frustrations (UNFPA 2012, DFID 2012, World Bank 2011). To mitigate this, training, continuing education and skills enhancement need to have measurable impacts on productivity and competency based outcomes. This will therefore require carefully planned skill updates in the form of clinical mentorship and on-the-job training so as to avoid disrupting service delivery.

Globally, the presence of Internet Communication Technology (ICT) has brought about other innovative ideas which can be explored. For example, ICT can be used in urban and peri-urban areas to develop the use of distance learning systems which, in turn, can improve skills and at the same time boost productivity. As a way of encouraging professional skills building, the Zambia Health Professions Council for medical doctors and Clinicians in Zambia have established a regulatory requirement that renewal of practising licensure and registration will require evidence of trainings and workshops attended in the previous year (HPCZ 2012). This is an initiative the General Nursing Council for Nurses and Midwives in Zambia can learn from and adopt to motivate and enhance competency building in the nursing staff.

11.4.3. Investing in research.

Further operational research is recommended to explore factors associated with skilled attendants' attitudes towards bereavement care after maternal and perinatal loss in both urban and rural areas. This could include investigation of health provider experience and perception of care and support services.

12. CONCLUSION

The study has revealed that the loss of a baby may be a very emotional and mentally devastating experience for the mother. Currently there is a great void in support services offered to address maternal distress; these are either unavailable or not fully utilized., Clinical care efforts are still at crisis level and to a greater extent still focused on physical aspects of childbearing, with particular emphasis on prevention and management of maternal and perinatal morbidities and mortalities.

The study has attempted to show that psychosocial and mental aspects of maternal health need the attention of professionals with adequate skills in counselling and bereavement care. These skills may go beyond the currently recognised work portfolio in nursing education. However, these services should be fully integrated in health care systems as they are a vital element of maternal health.

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14. APPENDICES

14.1 Appendix one: Guide for interview questions

Perinatal death in Lusaka, Zambia: Mothers' experiences and perceptions of care.

Preamble:

Thank you very much for accepting to come and share your experiences and for allowing me to talk to you about your experience of losing a baby in the health facility. I understand you have been through a great deal over the past days/weeks/months. I hope you can share your with me your experience and what it was like being in the hospital soon after losing your baby up to the time of discharge from the hospital.

Socio-demographic details

Age …… Employment (YES/NO)

Specify……

Single Mother/Married (YES/NO)

Specify……

Partner employment status if applicable…..……..

Parity…… sex of deceased infant …….

Questions to guide the discussion:

1. Where would you like us to start from?
2. Tell me about yourself.
3. Tell me about how you responded to labor pains and what you did once you went into labor
4. Tell me about your labor and delivery experience?
5. Tell me about how you were assisted with the delivery?
6. What things did the health provider do that was helpful?
7. What things did the health provider do that were not helpful
8. What was your experience of finding out the baby had died?
9. Tell me about how you have dealt with the loss?
10. How did the health workers help you deal with the loss?
11. How did your family members/spouse help you deal with the loss?
12. How did the community/friends do to help you deal with the loss?
13. What kind of assistance, services would you recommend for mothers in a similar situation in a health facility to assist them cope?
14. Have you been able to talk to someone else apart from me (Researcher) about your experience?
15. If so how did that person/institution do and if not why?
16. Is there anything else you would like to share with me about your experience?

14.2 Appendix two: Information Sheet

INTRODUCTION

My name is _____ I am a student at the University of Cape Town in South Africa. As part of my studies I am conducting a research focusing on the experiences of women following the death of a baby around the time of delivery until they are discharged home. I will be having discussions with women regardless of marital status or mode of delivery (Spontaneous Vaginal Delivery or Caesarean Section) experiencing pregnancy loss within one year of the time of this research and delivery by skilled workers at a health facility within Lusaka.

PURPOSE

This discussion is going to be done with other individual women who have gone through similar experiences of losing a baby at the time of delivery in a health facility setting. It will be done in Lusaka. The discussion will center on general questions to do with yourself and the experience you encountered during child birth that led to the untimely death of your baby. In particular, I am interested in your own personal feelings on the whole process, the care and support given to you and what you think about how you were treated in the facility.

PROCEDURE AND PROCESSES INVOLVED IN PARTICPATION

In terms of process, if you choose to participate in the study, I will ask you general questions about your social environment, education, work and access to health services. Thereafter, I will ask you to narrate your personal experience that led to the death of your baby at the health facility. The information will be used to make recommendation for women's health surrounding such a loss.

CONFIDENTIALITY

Personal information that would allow someone to identify you will not be obtained in this study. The questions we shall ask will only have an identification

number for use during the processing of data and not to identify you. All information and recordings used in our discussion will be locked in a cabinet and access will only be limited to the principal researcher.

DISCOMFORT THAT YOU MIGHT EXPERIENCE AS A PARTICPANT

As you narrate your experience, this may bring memories that might make you feel uncomfortable and make it very difficult to express yourself well. We do not wish for this to happen. However, we want you to feel very free to tell us if this is the case and if you feel you should not take part. In addition, if at any point during the interview you feel uncomfortable to continue, you can decide to pause or stop the interview at this time. It is completely up to you to decide this and indicate to me as the interviewer that you wish to pause or stop the interview process.

POTENTIAL BENEFITS IN RELATION TO YOUR PARTICIPATION.

It is hoped that through you and others participating in the study, we will be able to capture rich and valuable information that will assist us at national, regional and even global level improve the quality of services given to women after perinatal mortality in a health facility. Depending on the information collected, there may be need to conduct an even bigger research study to capture other issues not covered in this mini research study. You will not be paid for participating in this study.

PARTICPANTS RIGHTS

I would like to make clear that your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free not to answer any of the questions. You are also free to decide to stop participating during the interview/discussion any time you wish.

14.3 Appendix three: Informed Consent Form

My name is _____ I am a student at the University of Cape Town in South Africa. As part of my studies I am conducting a research focusing on the experiences of women following the death of a baby around the time of delivery until they are discharged home. The discussion will take at least one and a half hours. In the course of our discussion I wish to let you know that I will be taking notes.

I would like to make it clear that your participation in this study is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free to not answer any of the questions, and you can also decide to stop participating in the interview at any time you wish. In the process of the interview you may wish also to voluntarily withdraw or stop the interview without any repercussion.

Before we begin the interview, I need to obtain informed consent from you. This ensures that you agree to participate in the survey voluntarily and that you have obtained all the information needed in order to make an informed choice about you participation.

Please feel free to also contact the following persons if you have any questions or concerns about the study:

Dr. Lonia Mwape **Co- Supervisor in Zambia** Lecturer and Researcher The University of Zambia, School of medicine Department of Nursing Sciences P. O. Box 50110 Lusaka Tel: +260979093045 Email: loniamagolo@yahoo.com	**Dr Simone Honikman** **UCT Supervisor:** University of Cape Town Dept of Psychiatry and Mental Health Building B, 46 Sawkins Road Rondebosch 7700 tel: +27(0) 21 689 8390 Fax: +27(0) 86 648 2844 Cell: +27(0) 82 895 2416 simone.honikman@uct.ac.za
The Secretary ERES COVERGE Institutionalized Review Board, 33 Joseph Mwila Road Rhodes Park, LUSAKA	**Other Research academic queries to be addressed to:** Faculty of Health Sciences Human Research University of Cape Town Cape Town Republic of South Africa

Do you have any questions or any clarifications? If you do not have any/any more questions and agree to participate in the study, I ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate. This is the only place where your signature will be entered.

Thank you for your time.

I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the research. Any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to end the interview at any time.

---------- ----------

Signature/thumb print Date of interview

……

Signature of interviewer as Witness

14.4 Appendix four: Consent to Record Discussion

My name is _____ I am a student at the University of Cape Town in South Africa. As part of my studies I am conducting a research focusing on the experiences of women following the death of a baby around the time of delivery until they are discharged home. The discussion will take at least one and a half hours. I wish to let you know that from the commencement of our discussion, I will be recording our discussion using a tape recorder.

I would like to make it clear that your participation in this study is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free to not answer any of the questions, and you can also decide to stop participating in the interview at any time you wish. In the process of the interview you may wish also to voluntarily withdraw or stop the interview without any repercussion. The recorded discussion will be confidentially kept and stored in locked cabinet.

Before we begin the interview, I need your permission to allow me to record our discussion on a tape recorder.

Do you have any questions or any clarifications? If you do not have any/any more questions and agree to participate in the study, I ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate. This is the only place where your signature will be entered.

Thank you for your time.

I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the research. Any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to end the interview at any time.

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Signature/thumb print	Date of interview
……	……
Signature of Researcher as Witness	Date of Interview

14.5 Appendix five: Government Facilities and maternal services offered.

These selected Government Health Facilities in Lusaka central provide treatment at a subsidized government fee. The only gap anticipated encountered is the limited human resource experienced in these facilities.

No.	Name of Health Facility	Postnatal Services offered
1	**University Teaching Hospital**	ANC: 6 week postnatal check up Counseling Family Planning.
2	**Chainama Hills Mental Hospital**	ANC: Referral Hospital for mental health Counseling Psycho social Mental assessment Clinical care
3	**Matero Clinic, George clinic,** **Chipata Clinic, Chilenje Clinic** **Mutendere Clinic,** **Kalingalinga Clinic** **Bauleni Clinic, Chawama Clinic** **Makeni Clinic, Avondale Clinic.**	ANC: 6 week postnatal checkup. Counseling Family Planning Breastfeeding support groups.

Below are health professionals who offered to provide psychosocial support and counseling during the course of this research. A minimum consultation fee of 400 Rand or equivalent U$60 per extended future visits will be discussed where required between the consultant and the participant.

No	Name	Designation and details
1	Dr. Grave Singogo	Public Health Child Specialist – St Johns Medical Centre in Lusaka.(**Private Clinic**) Contact phone +260 955884341
2	Mrs. Raymunda Kabaso	Nursing Officer In-charge - St John Medical Centre in Lusaka.(**Private Clinic**) Contact phone +260 261247/ 261987/263032
3	Mrs. Rosemary Kabwe	Health Program Manager -Churches Health Association of Zambia/**Chairperson – Zambia White Ribbon Alliance for Safe Motherhood.** Contact Phone +260 97 9470015

15. ATTACHMENTS

15.1 Letter of approval from HREC UCT

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

29 June 2011

Sent via Internal mail & Email

HREC REF: 294/2011

Dr IM Singogo,
Mental Healht & Psychaitry
Red Cross Children's Hospital

Dear Dr Singogo,

PROTOCOL NUMBER 294/2011

PROJECT TITLE: HOW DO MOTHERS PERCEIVE QUALITY OF CARE FOLLOWING A PERINATAL DEATH? A STUDY OF MOTHERS EXPERIENES IN HEALTH FACILITIES OF LUSAKA, ZAMBIA

Thank you for submitting your new study to the Faculty of Health Sciences Human Research Ethics Committee

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

The researcher may want to consider incorporating the consent to tape record interviews in the main consent form to take part in the study. It seems unnecessarily burdensome to have to sign 2 consent forms. However, this may be a requirement for your local research ethics committee in Lusaka.

Approval is granted until 28 June 2012

Please submit an annual progress report (FHS016) if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

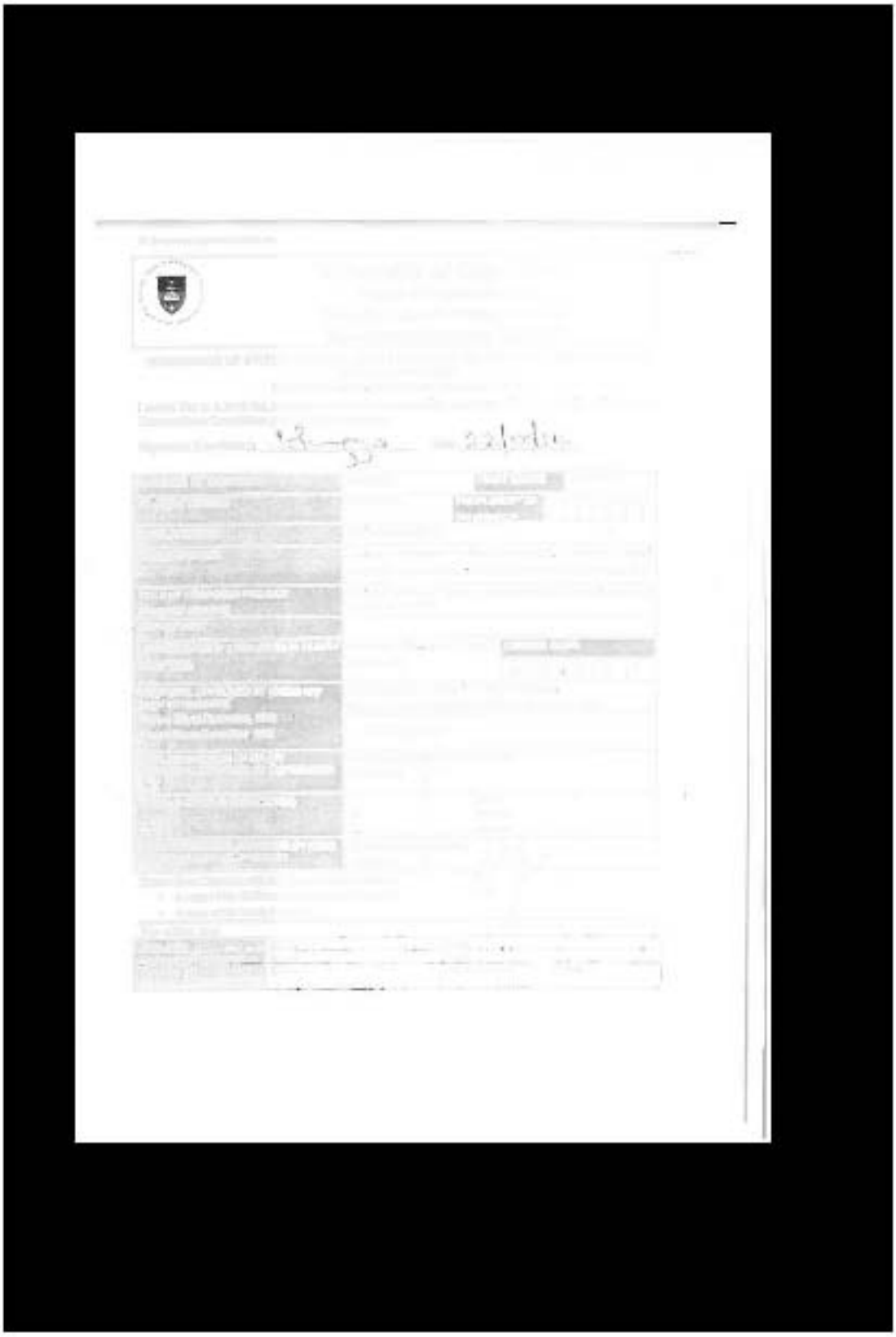
A/PROF MARC BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

15.2 Letter approving change of title from HREC UCT



15.3 Letter of seeking approval to change research title from ERES CONVERGE IRB

The chairperson
ERES CONVERGE IRB
33 Joseph Mwila Road
Rhodespark, LUSAKA

5th June 2013,

Dear Sir/Madam,

RE: 2012-APRIL-001 –RE - SUBMISSION OF END OF YEAR REPORT FROM

Following research data collection and on-going analysis, more information is being gathered bringing out actual circumstances leading to perinatal deaths within and out of facilities. Furthermore, perceptions of these circumstances have stimulated more information gathering in the areas of logistics and quality of care. Therefore, in order to harmonize this data it has become necessary to recast the initial title of the thesis and re-word it slightly in order to incorporate the current information that has been gathered as follows:

Old wording of research title: How do mothers perceive quality of care following a perinatal death? A study of mothers experiences in the health facilities of Lusaka, Zambia.

New wording: Perinatal death in Lusaka, Zambia: Mothers' experiences and perceptions of care.

Everything else remains the same. However, I will need more time go through each and every chapter and resubmit to my supervisor to facilitate a much more focused documentation. Consequently, this has resulted in coming up with a new activity plan as tabulated below requiring submission of final draft in November 2013 as opposed to my earlier timeframe of June 2013.

ACTIVITY:	Timeline/ submission to supervisors
Data collection process has been done. Currently analyzing data.	February 2013
Write up, finalize and hand in draft	March 2013
Receive corrections	March/April 2013
Incorporation of supervisors comments to thesis chapters	
Incorporation changes to chapter one	May 31st
Incorporation changes to Chapter two	June 14th
Incorporation changes to Chapter three	June 28th
Incorporation changes to Chapter four	July 19th
Incorporation changes to Chapter five	July 29h
Incorporation changes to add discussion chapter	Aug 9th
Incorporation changes to Chapter six	Aug 16th
Consolidation of whole proposal draft for final comments	Aug 30th
Consolidation and integration of final comments	October 25th
Final Submission of dissertation to UCT	November 13th 2013

Yours sincerely,

Irene Miti Singogo

15.4 Letter approving change of title from ERES CONVERGE IRB

ERES CONVERGE

33 Joseph Mwilwa Road
Rhodes Park, Lusaka
Tel: +260 955 155 439
+260 955 155 434
Cell: +260 966 765 503
Email: eresconverge@yahoo.co.uk

I.R.B. No. 00005948
FWA No. 00011697

13th February, 2014

Ref. No. 2012-April-003

The Principal Investigator
Mrs. Irene Miti Singogo
Ndola Baptist Church
Plot No. 1004 Broadway
P.O. Box 70343,
NDOLA.

Dear Mrs. Singogo,

RE: **How do mothers perceive quality of health care following a perinatal death? A study of mothers experiences in the health facilities in Lusaka, Zambia.**

Reference is made to your letter dated 9th September, 2013.

Renewal for the study has been approved as well as the proposed amendments: the new expiry date is 17th **May, 2014.**

Yours faithfully,
ERES CONVERGE IRB

[redacted]

Dr. E. Mfula-Nkanda
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD
CHAIRPERSON