FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' PERSPECTIVE AND HEALTHCARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL, 2020. A DESCRIPTIVE CROSS-SECTIONAL STUDY.

A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT FOR THE AWARD OF THE DEGREE OF MASTER OF MEDICINE IN OBSTETRICS AND GYNAECOLOGY

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I would like to acknowledge God for granting me an opportunity to do this study, my Supervisors for their guidance and tireless efforts. To my family especially my late son, thank you for giving me a chance to smile again, to my participants thank you for sharing your experiences, to the obstetrics and gynecology department, thank you for allowing me to do this study.

DEDICATION

This work is dedicated to my family especially my late son Giovanni Mario who was born prematurely at 29 weeks after an eclamptic fit and stayed with us for 149 days. Through his loss, I witnessed the pain mothers experienced after child loss, the many dreams that are shattered when a pregnancy ends prematurely, and the pain of walking home empty handed. It is also dedicated to my husband who really supported me during the difficult season, for also making me understand that its ok to say that all that I achieved that year is 'I survived'. It is also dedicated to still a mum support group and Tears foundation especially the Kenyan Chapter: we shall no longer discuss it behind closed doors, it will be our turn to be heard, that any other mother who goes through this tragic path will get the proper bereavement care they need. It is also dedicated to the healthcare professionals' in Obstetrics Unit that work tirelessly to improve maternal and neonatal outcomes.

LIST OF ABBREVIATIONS AND ACRONYMS

ERC:	Ethics Research Committee
HCW:	Health Care Worker
KDHS:	Kenya Demographic Health Survey
KNH:	Kenyatta National Hospital
LMIC:	Low Middle-Income Countries
PL:	Perinatal Loss
PMR:	Perinatal Mortality Rate
PPD:	Postpartum Psychosis Disorder
SDG:	Sustainable Development Goals
TRIG-F:	Texas Revised Inventory of Grief
UNICEF:	United Nation Children Fund
WHO:	World Health Organization

DEFINITION OF OPERATIONAL TERMS

Bereavement Care: As per medical dictionary it is the formalized care and support given to benefit a bereaved individual, to help him or her deal with the emotional and practical problems following the loss of a loved one.

Neonatal Mortality: According to the WHO it's the death of a neonate during his or her first 28 days of life (0-27 days).

Neonatal Mortality Rate: As per the WHO it's the number of neonatal deaths per 1000 live births, calculated as the neonatal mortality in a county, state, or country at a specific time point divided by the total live births in the county, state, or country over the same time point multiplied by 1000.

Perinatal Mortality: According to the WHO, it refers to the number of stillbirths and deaths starting at 154 days or 22 completed weeks of gestation up to seven days after a delivery

Perinatal Mortality Rate: As per the WHO it's the number of still births and deaths in the first week of life per 1,000 total births.

Disclaimer! The word mother and woman has been used interchangeably in this document

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ABSTRACT

Background: Within a year of a loss of pregnancy, about 20% of mothers develop some form of psychological disorder, with anxiety and depression being the commonest. If the disorders are not managed, progression to serious psychiatric disorders such as postpartum psychosis disorder (PPD) has been reported. PPD afflicts 1-2/1000 women of a childbearing age in the first two to four weeks following an unsuccessful pregnancy and can affect the future pregnancies of bereaved mothers and relationships with infants. To prevent such outcomes, support for bereaved mothers after a perinatal loss, which includes delivery of bad news with sensitivity, provision of a private space for mourning, and referrals for psychological support are some components of bereavement care. However, whether healthcare workers at Kenyatta National Hospital (KNH) adhere to these standards is not understood as the framework for bereavement care after perinatal loss has not been evaluated. Moreover, the bereavement care experience of patients has not be evaluated in this setting. We used the Donabedian model to evaluate its structure, processes, and outcomes in this health facility.

Broad Objective: To evaluate the framework for bereavement care after perinatal loss at Kenyatta National Hospital as perceived by the affected parents and health care providers.

Methodology: This was a mixed methods study at KNH maternity unit. Seventy-three (73) parents who had experienced a stillbirth were recruited consecutively as they were identified at KNH, a bereavement care experiences questionnaires completed, and the participants offered the opportunity to participate in parent/couple in-depth interviews or a Focus group discussion scheduled on a later date. After consenting, a pretested questionnaire was used to capture the socio-demographics of the parents and healthcare providers, reproductive characteristics of women such as parity, any obstetrics complication, characteristics of infants such as the gestation at birth, sex, and cause of death. Bereavement care structure and process was also evaluated. The perceptions of parents on intrapartum care and the postpartum care offered during labor and delivery was also captured and a focused group discussion scheduled with 7 randomly chosen parents. Five couples (10 parents) took part in in-depth interviews (IDIs). The In-depth interviews and focus group discussion (FGDs) were conducted using semi-structured interview guide and moderated by the research assistant. Healthcare workers (65) who were randomly recruited also completed an observational checklist on best bereavement care practices and key informant interviews moderated and recorded by the principal investigator (PI) for ease of reference. Quantitative data was analyzed using Microsoft Excel. Frequency-distributions and proportions have been used to explain demographic and reproductive characteristics. IDIs and FGDs recordings were transcribed and data analyzed using content analysis to arrive at themes. Dedoose version 8.0.35 was used for qualitative data analysis while STATA Version 15 was used for quantitative analysis.

Findings: Of the 73 parents recruited, 71 (97%) were female, while 75% had post primary education. Most were Christian (97%), employed (49.0%), and received antenatal care (ANC) (96%). The median (interquartile range) number of contacts reported to be 4 (3-5). Only 34% had pregnancy complications, mostly hypertensive disease in pregnancy (54.0%). Overall, 56.8%, 41.3% and 34.8% reported positive bereavement care experiences in the antepartum, intrapartum, and postnatal periods respectively. In most cases, the loss of a child was not communicated effectively by health care workers (HCWs). counseling was necessary yet lacking, while families, especially spouses were not engaged in bereavement care. In most cases, a conducive environment for mourning loss was lacking. Of the 65 HCWs interviewed, 66% were female and 63% were nurses in the maternity unit. Only 17% had received training on bereavement care with only 44.3% were adhering to the best practices of bereavement care on how to handle patients who experience perinatal loss. Around 94%

did not engage a next of kin when breaking the bad news, while 83% reported unavailability of a separate space/room when breaking bad news. Overall, the bereavement care structure at KNH was deficient in many aspects with lack of training on bereavement care, lack of a bereavement care protocol, and high patient volumes identified as key impediments during key informant interviews.

Conclusion: Training Healthcare providers on bereavement care is an important step towards improving the standard of bereavement care services provided to parents who have gone through perinatal loss. Providing counseling as a minimum service for parents/- families will help understand their needs and the best possible approach to meeting those needs. Development of a bereavement care protocol is crucial so as to align the needs of these parents.

Recommendations: There is a need to provide training for bereavement care to health workers as its delivery is suboptimal. The bereavement care structure at KNH should also be updated as the existing framework does not have a positive bearing on the quality of life of bereaved patients.

CHAPTER ONE

1 INTRODUCTION

1.1 Background

Perinatal mortality refers to the number of deaths of neonates in the first seven days of life and stillbirths for every 1000 live births (1). Stillbirths are referred to as reported deaths after 28 weeks of gestation. Although mortality rates in under five years have drastically reduced over the past 20 years in developing countries, perinatal mortality tends to follow a reciprocal correlation and inconsistent patterns and therefore, present a huge burden (2). According to the Kenya Demographic Health Survey (KDHS) of 2003, perinatal mortality rate stands at 40 deaths per 1000, with the highest rate reported at the Coastal region at 58/1000 deaths. Western has the lowest rate at 28/1000 deaths (3).

Even though global records suggest that mortality of under-fives has declined, the incidence of neonatal mortality remains high. In a study by Liu et al. in 2012, neonatal mortality constituted around 44% of deaths of under-fives (4). Target 1 and 2 of the Sustainable Development Goals (SDG) 3 champions for healthy living for all humans by 2030. It also champions for a reduction of the maternal mortality ratio globally to less than 70/100,000 and the ending of preventable deaths of newborns and under-fives. To date, all countries strive to lower the under-fives mortality rate to 25/1000 and neonatal mortality rate to less than 12/1000 by improving antenatal, intrapartum, and postpartum perinatal or maternal care (5). Moreover, because a correlation between maternal and perinatal outcomes exists, programs designed to address improvement influence outcomes, especially of intrapartum care and management of hypertension (6–8). Notably, pre-term birth, hypertensive disease in pregnancy, infections, and intrapartum asphyxia contribute the most to perinatal mortality in middle and low incomes (LMICs) (6,9). According to UNICEF observation, only 43% of deliveries in the developing countries occur in modern hospitals as compared to 68% of all deliveries worldwide (10). Therefore, mitigation of perinatal mortality still stands as a burden in the developing countries.

Perinatal loss is a painful moment for mothers than any other form of bereavement because it is unexpected, often sudden and sometimes unexplained (11). There is often dismissal of perinatal loss as a non-important factor in bereavement by the society, therefore it can in turn be a traumatic event overlooked even by healthcare professionals (9). Bereavement is a disorder that often increases the risk of negative physical outcomes in parents: weight loss, decreased food intake, immune system impairment and or mortality risk being the most notable (12). Within a year of a loss, it is estimated that 20% of mothers suffer some form of psychological disorder such as anxiety or depression. This can lead to psychiatric disorders such as postpartum psychosis disorder (PPD), which has been shown to affect the future pregnancies of bereaved mothers and relations with the next infant (13–15). The disorder has been observed in close to 1–2 per 1000 childbearing women in the first two weeks to a month following an unsuccessful pregnancy (16,17). It said that the onset of PPD might be sudden and acute in nature (18). In India it is estimated that incidence of PPD is about 11% of women in the rural compare with westernized families where it varies at about 10–15% of all mothers getting affected. In India, the incidence of PPD in a community-based prospective study of rural women was 11%, which was comparable to the 10-15% rate reported in women in South Africa (6). Incidence of PPD is highest among adolescent women aged <25 years at 81% (19).

To avert the consequences of perinatal loss both the mother and the caregivers play a crucial role in decision-making. The caregivers, through training and with proper guidelines or policies provided by the hospital, deliver objective solutions to the bereaved mothers. Grief associated mental disorders in patients seem to be under-diagnosed and often have far-reaching consequences for mothers, their future infants, and their relationships with their partners and other family members. Early screening and diagnosis are the first steps in prevention of stillbirths. Healthcare professionals have a mandate to screen mothers regularly and diagnose such conditions during hospital visits (antepartum and postpartum) using simple laid-down guidelines. Through this study, we evaluated the framework of bereavement care after perinatal loss at Kenyatta National Hospital, following the Donabedian model

that was developed by Donabedian in 2005. This model proposes evaluation of three components of service delivery - structure, process, and outcomes - to judge improvements to patient's welfare. As per the model, the three components are interrelated and thus form a basis for what should be done to improve service delivery to patients, which has a positive bearing on quality of life (20). The model has been used to evaluate health care quality since 1966 and is therefore a reliable framework (21).

CHAPTER TWO

2 LITERATURE REVIEW

2.1 The Epidemiology of Perinatal Mortality

According to World Health Organization (WHO), the period of perinatal mortality (PM) starts at 154 days or 22 completed weeks of gestation up to seven days after a delivery (22). The WHO also indicates that fetus born dead after 14 completed weeks of gestation are stillborn and that perinatal mortality or deaths occur during the first week of life (or 0-6 days) after completion of 20 weeks of fetal gestation. Perinatal mortality rate is one of the major indicators for the quality of prenatal care, delivery care, and the early infant care practices of health institutions (23,24). In 1996, the perinatal mortality rate of below 10/1000 in the developed world, which was considerably lower than the 40-120/1000 live births in sub-Saharan Africa (SSA) (30). In 2008, a United Nations Children's Fund (UNICEF) report suggested that the global burden of mortality in children was close to four million annually during the first four weeks of life, with a majority of the reported deaths (99%) happening in LMICs – 30% of which were in SSA the Asia and third in Latin America (25).

2.2 Factors that Influence Perinatal Mortality

The 2014 KDHS on infant mortality rate indicated that approximately 39 deaths of children occur for every 1,000 live births, with the mortality rate found to be significantly higher in under-fives (52/1000). The prediction indicated that approximately one child in every 26 Kenyan children dies before his or her first birthday, while about one in every 19 die before they reach the age of five, with several risk factors identified. In SSA and South-Central Asia, for instance, complications of preterm birth, birth trauma, asphyxia, severe congenital malformations, and trauma are linked with a high risk of stillbirth (25). The main obstetric complications are placenta previa or abruption, antepartum hemorrhage, eclampsia or pre-eclampsia, while labor related conditions include cord prolapse, uterine rupture, low birth weight, multiple pregnancies, and preterm delivery (26–28).

In the sub-Saharan Africa, other unknown predisposing factors are poor maternal educational level, which may be related to poor nutritional status, therefore correlating to poor health bringing about poor perinatal outcome. Birth spacing intervals of under two years can also contribute to poor maternal nutritional, which in turn leads to low-birth-weight infants and perinatal death. Advance maternal age or extremely low conception ages below 18 years can also lead to perinatal mortality rates PMR (10,26–28). Other predisposing factors leading to perinatal death are related to the maternal health status through acquisition of certain ailments such as essential hypertension, pregnancy-induced diabetes mellitus (DM), malaria, anemia, tuberculosis, and or Acquired Immune Deficiency Syndrome (AIDS). These factors have been linked with a high risk of low birth weight, intra-uterine growth retardation, and perinatal death. Perinatal loss can be a devastating experience threatening a mother's mode of comfort and well-being, resulting to physical and psychological emotions (29). At KNH, 5025 perinatal deaths were reported from 2015 and 2018 (unpublished data, Health Information Department, Kenyatta National Hospital).

2.3 Parental Bereavement Care Experiences

Bereavement after a miscarriage or stillbirth is a long and arduous process, associated with changes in psychological health. Psychiatric disorders such as anxiety disorders, depression, insomnia inertia, somatic symptoms, and hyperactivity have been reported, and found to affect the lives of women in this delicate state negatively (29,30). The incidence of such adverse outcomes increase with improper bereavement care (31,32), with several recent studies stressing the need for optimal bereavement care to grieving parents. From published data, the bereavement care experience of parents varies widely, depending on the timing of a stillbirth, engagement by healthcare providers, and the structures or systems of bereavement care or support implemented in different localities and centers of health.

While evaluating the bereavement care experiences of partners who delivered a stillbirth, Peters et al. (33) demonstrated the need for provision of culturally appropriate and meaningful bereavement care after a stillbirth, as most affected parents thought it was lacking. From the review of literature, a

majority of grieving parents reported suboptimal bereavement care after a stillbirth, as they felt staff did not validate their emotions nor provided clear and informative bereavement care after delivery. Moreover, because the timing of information dissemination was distressing, parents wanted guidance and support in decision-making and accommodation of their cultural practices in bereavement care, which seemed to be largely ignored.

In another systematic review of health care worker and parental experience with stillbirth, Ellis et al. (34) found similar results from data derived from mixed method, qualitative, and quantitative research studies. From the review of published literature, Ellis and colleagues identified the following broad themes that should inform bereavement care practices as reported by parents: After a stillbirth, for instance, a majority of parents required support with memory making through provision of mementos or videos and prioritization of stillbirth care, which were lacking. Furthermore, parents reiterated the need for discussions before vaginal births, maximization of privacy without abandonment, and hosting post-natal and post-mortem discussions in an accommodative and sensitive manner. Overall, from the reports of the parents and staff, creating clear care pathways with supportive systems and structures could help affected parties to cope with the loss of children better and improve outcomes.

Finally, while evaluating the perceptions of parents on bereavement care after the death of a child, Michon et al. (23) showed the importance of bundling psychological support with bereavement care for parents struggling with the death of a child. In the comparative study of 71 bereaved parents from 43 families, grief, as measured using the Texas Revised Inventory of Grief (TRIG-F), was statistically higher among parents who lost their children in the perinatal period, mostly among mothers. Because grieving was associated with a higher incidence of psychological distress, affected partners reiterated the need of psychosocial support from health care providers, as they saw them as a source of hope during their time of gloom.

Therefore, from the testimonials of parents, a lot is expected from health care providers of bereaved couples through interaction, no matter how unprepared they are (35). According to the culture care diversity and universality theory, health care providers should go beyond their thinking to a much more holistic and multicultural perspective (36). Studies suggest that the bereavement care services offered in hospitals focus on the reduction of harm and sorrow for the bereaved families, but do not cater to the needs of healthcare providers (37,38). It therefore is crucial for hospitals to care for and support health professional to improve the standard or quality care provided to the bereaved mothers.

2.4 Health Care Workers Bereavement Care Experiences

Grief is not considered an illness. However, it is the responsibility of hospitals and the providers of healthcare to make sure bereaved couples get the appropriate care before and after the demise of their babies. One hundred years ago, the births and deaths of most babies took place at home. Nowadays, most babies are born in hospitals and die in hospitals. Few investigations have been done to establish the effect provision of bereavement care to couples have on nurses who provide such care. A few studies have found that obstetric caregivers may undergo a diverse range of effects, which include crying, anger, fear, sadness, intense sorrow, grief, guilt, and nightmares (37,38). Furthermore, the bereavement care experiences of health care workers and parents seem to be related (34), with system barriers, the lack of sufficient knowledge and emotions described as barriers for service provision.

Little and inconclusive reports give the perceptions of the emergency department and surgical nurses towards care provision to bereaved mothers, even though emergency department nurses provide the most care to perinatal loss mothers (39). It has been established that nurses who care for multiple bereaved mothers have high odds of developing work-related psychological disorders (39,40), and thus find themselves unable to perform at work (41). Bereaved women also have adverse reactions whenever the bereavement care offered by health professionals does not satisfy their needs. Anger, and the feeling of seclusion and victimization have been reported (42–45).

Caregivers might also be affected by the traumatic events though few studies have evaluated to this effect. In some studies, it was found that positive attitudes about care offered after a perinatal loss were related to a past bereavement education, support from groups, family and colleagues. This was strongly supported by hospital-based policies given by the nurses (42–47). It is for this and other factors that led the WHO to make a proclamation on the prevention and elimination of disrespect and abuse during delivery in health facilities (48). The statement built a more respectful and comprehensive care strategy for the newborn and not only to the time of death but also covered maternal and perinatal loss grieving (48,49). The provisional care of bereaved mothers after the loss of a child can negate short and long-term negative outcomes (50).

2.5 Conceptual Framework

According to the Donabedian Model, information about quality of care in health is in three categories – the structure, the process, and the outcomes. The structure covers the context in which there is delivery of care such as staff, the hospital buildings, equipment, or financing. The process covers the interactions of healthcare workers and patients throughout delivery of healthcare, while the outcomes are the effects care offered by healthcare workers have on the health of the population or of patients.

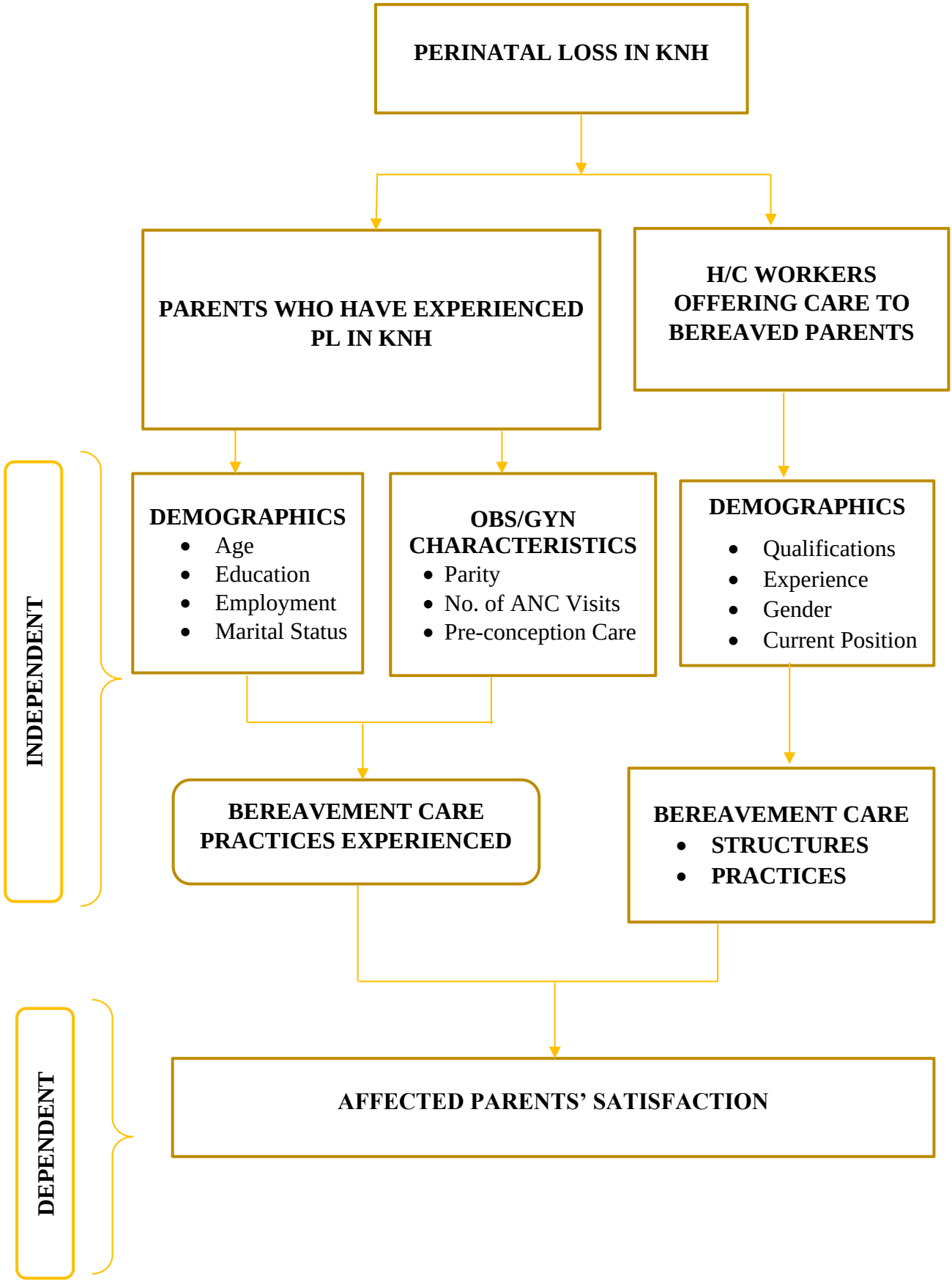

Figure 1. Conceptual Framework

2.6 Theoretical Framework

The research majored on qualitative method, which may be located in any known paradigms, positivity, interpretational and critical (51,52). A paradigm is perceived to be a structure with ideas providing a conduit of observing or creating assumptions that are of scientific aspects. This path can provide questions and puzzles to be revealed and interpreted also indicating the research methods to be used (51). Where paradigms are established rules and techniques that are scientifically discovered in any community, purposefully to identify and illuminate a problem.

The paradigms can further install some reasonable direction in solving the problems, therefore, providing productive results and justification that are acceptable to the scientific community for further reference. As noted by Sale *et al*; while revisiting the quantitative-qualitative debate on implications for mixed-methods research' Quality and Quantity, this was because quantitative paradigm is known to be based on positivism (53). This concept is emphasized by defining the empirical research: as that which participants can be reduced to empirical indicators that are representative of the truth and an ontological position of a quantitative paradigm, which indicated that the truth is non-existent. Thus, the ideal objective exists independently in the perception of humans.

At the epistemologically is when both the person under investigation and the investigator or investigating body are independent entities. It therefore means that the investigator can only examine a phenomenon without compromising or being influenced by a phenomenon. As such, the investigator can study a factor without being influenced by it or influencing it. Thus, as Guba and Lincoln ably put it, “the inquiry happens via a one-way mirror.” Therefore, following this framework, the intention was to describe the framework for bereavement care after perinatal loss from the affected parents’ perspective and healthcare providers’ perspective at Kenyatta National Hospital (54).

2.6.1 Theoretical Framework on Phenomenology

The study explored quantitative and qualitative research methodology to generate data for the final analysis from both the bereaved parents and health care workers at KNH. It is good to note that qualitative studies require a small sample size, unlike in quantitative research. The reason for this is that qualitative interviews aim to gain a deep understanding of an issue that interest researchers. Moreover, in-depth interviews often do not rely on a hypothesis test but concentrate more on issues of inquiry. The aim of in-depth interviews and the grounded theory, therefore, is to categorize qualitative data and evaluate the relationships between the identified categories based on a phenomenon of the participants (55).

2.6.2 Phenomenology

Phenomenology is an exploratory research technique in which the perceptions of participants guide data collection, which are then correlated to the perceptions of caregivers. One on one interviews in qualitative studies are ideal due to their ability to facilitate collection of personalized information. Therefore, engaging with couples and the caregivers interactively increased in-depth gathering of information. Phenomenology is believed to have been in existence from the 20th century discovered by two-by-two philosophers Martin Heidegger studying the earlier writings of Edmund Husserl. Therefore, the scientific tool of phenomenology revolves around academic areas of psychology and philosophy and is therefore suitable for describing the experience of humans. Phenomenology is a qualitative technique, which can describe experience of humans with a given phenomenon (56,57).

The method allows an investigator to evaluate the perspectives, perceptions, understandings, and or feelings of individuals who live with or have experienced a certain situation and or phenomenon of interest and direct the description and investigation of phenomena as experienced by people who are living those experiences (57). The study was conducted using in-depth interviews with a small sample of respondents. Phenomenology investigations create an understanding of how individuals experience a given phenomenon or situation. The interviews involve in-depth observations and or interviews and

often require 10 or less participants who can respond to open ended questions and describe their experiences fully from their unique perspectives. During such interviews experiences of participants are evaluates with no regard to their cultural or social norms, preconceived ideas, and or traditions about the experience. Instead, it focuses on four aspects of life, which include the lived time, space, body, and human relations. It also involves collection and analysis of qualitative data to identify themes and generalize on how a certain phenomenon is perceived (57).

2.7 Justification

Globally 2.6 million perinatal deaths occur annually (2). At KNH, the perinatal mortality rate is approximately 7% despite adoption of free maternity care in 2017. After delivering a stillbirth, about 20% of mothers develop some form of psychological disorder, with anxiety and depression being the commonest. If the disorders are not managed, progression to serious psychiatric disorders such as postpartum psychosis disorder (PPD) are common. PPD afflicts 1-2/1000 women of a childbearing age in the first two to four weeks following an unsuccessful pregnancy (16,17). Perinatal Loss can also affect the future pregnancies of bereaved mothers and relationships with infants. To prevent such outcomes, support for bereaved mothers after a perinatal loss, which includes breaking of bad news with sensitivity, provision of a private space for mourning, and referrals for psychological support are recommend components of bereavement care. However, whether healthcare workers at the Kenyatta National Hospital (KNH) are adhering to these standards is a matter for speculation.

Framework of bereavement care have not been evaluated scientifically at KNH. Describing the experience of parents after a perinatal loss can offer insights on how to improve the quality of perinatal bereavement care offered in Kenya at KNH. The data will also contribute to the development of action guidelines for perinatal loss and bereavement care in the facility, which can improve the quality of life (QOL) of and health care delivery for those parents who have experienced a perinatal loss.

2.8 Research question

What is the framework for bereavement care after perinatal loss at KNH in 2020?

2.9 Broad Objective

To evaluate the framework for bereavement care after perinatal loss at KNH in 2020.

2.10 Specific Objectives

i. To describe bereavement care experiences of affected parents after perinatal loss in KNH.
ii. To evaluate healthcare providers' adherence to the recommended best bereavement care practices when attending to parents who have experienced perinatal loss in KNH.
iii. To determine the structure in place for bereavement care after perinatal loss in KNH.

CHAPTER THREE

3 METHODS

3.1 Study Design

This was a mixed method study evaluating the framework for bereavement care after perinatal loss at KNH in 2020 based on the perspectives of parents and healthcare providers.

3.2 Study Site

The study was conducted at the Kenyatta National Hospital – a public hospital that serves as the main referral hospital in Kenya and a teaching hospital for the University of Nairobi, College of Health Sciences. Located 3.5 kilometers west of the central business district of Nairobi, KNH serves over one million people from Nairobi and its environs in its clinics, general wards, and maternity unit. In 2018, 10,995 deliveries were reported at KNH. The perinatal mortality rate was estimated to be around 8.1% (887) in the same year, with 5.1% (557) of all births being stillbirths. KNH has a bustling Neonatal Birth Unit (NBU) with an intricate record archival system, which makes it a suitable site for our study. Furthermore, because KNH oversees many deliveries every month of patients from Nairobi County or its environs, access to bereaved couples was not a challenge for the principle investigator.

3.3 Study Population

3.3.1 Health Care Workers

We approached for recruitment all heath care workers (nurses and medical doctors) providing bereavement care to parents who had a stillbirth in the maternity unit. At KNH, it is estimated that 287 health care workers work in the maternity unit/labour ward. These healthcare providers were included because part of their duty is provision of bereavement care for the affected parents. Their responses had both qualitative and quantitative input in the study. All participants met our inclusion criteria.

3.3.1.1 Inclusion Criteria

- Provision of bereavement care to parents
- Practiced at KNH maternity unit for at least one year
- Provided informed consent for participation

3.3.1.2 Exclusion Criteria

- Decline to provide informed consent
- Newly deployed at KNH maternity unit

3.3.1.3 Sample Size

$$n = \frac{Nz^2p(1-p)}{E^2(N-1) + z^2p(1-p)}$$

Definitions:

n= sample size

p= prevalence of stillbirth (assumed to be 5.1%)

z= standard normal variate for 95% confidence level

E= precision

N= population size

Assumptions:

p= 5.1%

z= 1.96

E= 5.0 %

N= 281 (from unpublished data by the Health Information Department at Kenyatta National Hospital)

Estimated sample size = 59 healthcare workers

After an adjustment by 10% to cover non respondance, sample size = 65 healthcare workers

3.3.2 Parents

All parents who experienced a stillbirth at the KNH in 2020 qualified for the study. About 887 perinatal deaths occurred in 2018 at KNH, 557 (6.3%) of which were stillbirths. The value for stillbirths (557) was our reference population. Their responses had both qualitative and quantitative input in the study.

3.3.2.1 Inclusion Criteria

- Had a stillbirth at 28 weeks above at KNH
- Willing participants by providing informed consent
- Lived within a 50-kilometer radius from KNH for easy access to get care and for focus group discussions.

3.3.2.2 Exclusion Criteria

- Under 18 years old
- Known mental health disorder diagnosed before pregnancy

3.3.2.3 Sample Size

$$n = \frac{Nz^2p(1-p)}{E^2(N-1) + z^2p(1-p)}$$

Definitions:

n= sample size

p= prevalence of stillbirth (assumed to be 5.1% from unpublished data by the Health Information Department at Kenyatta National Hospital)

z= standard normal variate for 95% confidence level

E= precision

N= population size

Assumptions:

p= 5.1%

z= 1.96

E= 5.0 %

N= 557 from unpublished data by the Health Information Department at Kenyatta National Hospital

Estimated sample size = 66 parents

After an adjustment by 10% to cover non-respondents sample size = 73 parents

3.4 Sampling Procedure

3.4.1 Quantitative

Purposive sampling was used to recruit the participants: Parents who experienced a stillbirth at KNH during the study period were allowed to be participants in the study as long as they met the inclusion criteria and consented to the study. Healthcare providers in labour ward, tasked with offering care to parents after stillbirth at KNH, who met the inclusion criteria and offered consent for the study were recruited until we attained our sample size.

3.4.2 Qualitative

Purposive-random sampling was used to select the parents for the interviews: For the In-depth interviews consenting parents who had filled the questionnaires and were couples were allowed to participate while for the Focused Group Discussion consenting parents who had filled in the questionnaires participated. Purposive sampling was used to select participants as follows:

- In-depth interviews- 10 affected parents that were couples
- Focused Group Discussion-10 affected parents
- Key Informant Interview-3 Healthcare Workers

3.5 Recruitment Strategy

3.5.1 Affected Parents

Seventy-three (73) parents were identified from labor ward, recruited and requested to fill in a written informed consent form. Thereafter they completed the questionnaire at discharge point in the postnatal ward or during their first postnatal visit, which was after two weeks. Recruitment of parents was done sequentially until we attained our required sample size. Ten (10) randomly selected parents were also subjected to a focused group discussion and in-depth interview within the first postnatal visit.

3.5.2 Health Care Providers

Sixty-five (65) healthcare providers working in labour ward and who met the inclusion criteria were identified since they encountered these parents often in their line of duty. Upon completing the written informed consent form, they filled the questionnaires.3 Key informants were, thereafter interviewed.

3.6 Data Variables

3.6.1 Outcome and Independent Variables

Table 1. Outcome and independent variables

Outcome variables			**Source of Data**
Affected Parents satisfaction with the quality of bereavement care offered after PL(affected parents' perspective) based on a study questionnaire		Excellent Good Poor	Questionnaire, In-depth interview guide, and FGD guide.
Healthcare providers satisfaction with the quality of bereavement care they provide to patients with PL (Healthcare provider perspective) based on a study questionnaire		Excellent Good Poor	Questionnaire and Key Informant Guide
Independent variables			**Source of data**
Affected Parents	Age	18-30	Questionnaires
		31+	
	Marital status	Married	
		Single	
	Parity	Primigravida	
		Multigravida	
	Religion	Christian	
		Muslim	
	Education	Primary	
		Secondary	
		Tertiary	
	Preconception care	Yes	
		No	
	Antenatal clinic attendance	Yes	
		No	
	Weight of baby	Premature	
		Normal	
		Macrosomia	
	Sex of baby	Male	
		Female	
	Information dissemination	Consultant	
		Junior doctor	
Healthcare providers	Age	18-30	Questionnaires
		31+	
	Gender	Female	
		Male	
	Staff cadre	Consultant	
		Resident	
	Training on bereavement	Yes	
		No	
	Child loss	Yes	
		No	
	Religion	Christian	
		Muslim	
		Buddhist	
		Other	
Structures in place for bereavement care		key informant interview guide	
Bereavement Care practices		Questionnaire, In- depth interview guide, key informant interview guide, and FGD guide.	

3.7 Data Collection and Management

3.7.1 Quantitative

Structured questionnaires were developed. The first one was used to collect primary data from parents. The questionnaire was administered by the principal Investigator in person for all. It was broken down into four sections to streamline data collection. The first section captured the socio-demographic and obstetrics characteristics of parents such as age, marital status, gender, parity and preconception care. The second, third, and fourth sections of the questionnaire captured the antepartum, intrapartum, and post-partum bereavement care experiences of parents after having a stillbirth. The second questionnaire was for healthcare workers; it was self-administered and was used to evaluate their demographics (age, gender, years of experience in the unit) and their adherence to best bereavement care practices. The questionnaires were then kept in secure place for safety and confidentiality. Both questionnaires were pre-tested to ascertain their reliability and validity before using them to collect data in the definitive study.

3.7.2 Qualitative

In-depth interview and Focused group discussion guides were used for conducting in-depth interview and focused group discussion with parents respectively. Participants who were recruited and had completed the questionnaires were offered a chance to participate in the IDIs or FGD on a later date. Those whose spouses were not at the hospital at the time of recruitment confirmed availability of spouses for IDI scheduling, 10 other parents confirmed willingness to take part in the FGD. These parents were contacted via phone two days before interviews, saturation was confirmed by the time we were winding up the interviews. A key interview guide was also used to interview key informants in the maternity unit. All these sessions were audio recorded and the recordings stored in a secure place for safety and confidentiality.

3.8 Data Analysis

3.8.1 Quantitative data

The questionnaires were reviewed for completeness and accuracy. Data was entered into an access database and then exported to excel. The data was then analyzed using STATA Version 15. Proportions were computed for categorical variables such as gender, education level and marital status while measures of central tendency were obtained for continuous variables such as age and parity. The frequencies and cumulative percentages of bereavement care practices at intrapartum, postpartum, and on discharge were also computed and presented in a table

3.8.2 Qualitative data

All the audio recordings were transcribed verbatim, translated to English as needed and personal information de-identified. Thereafter the completed transcripts were uploaded to Dedoose ***version 8.0.35*** for analysis. Inductive and deductive approaches to content analysis were then used to arrive at themes. The transcripts were coded by 2 independent coders i.e. the research assistant and the principal investigator, each coding 2 transcripts until consensus was reached. Progressive coding was done, line by-line, gauged and central themes extracted from statements. For the remaining transcripts, one coder did primary coding with the other coder doing secondary coding, the themes were then agreed upon by both coders. Themes were then revised to sub themes and reports abstracted to findings.

3.10 Ethical Considerations

Authorization and approval were obtained from the KNH Research Ethics Committee to conduct the study (Protocol number P703/08/2019). A written informed consent was obtained from all the study participants. All identifiers such as names of persons were also removed from transcripts. The filled checklists and questionnaires were kept in secure place for confidentiality after data entry; cleaning

and dissemination of results. Parents overcome by grief were referred for psychosocial support. Enrolment was voluntary and participants allowed to withdraw at any time without any consequences.

3.11 Study Results Dissemination Plan

Data will be compiled in a thesis and submitted to the department of obstetrics and gynecology of the University of Nairobi. A manuscript will be generated from study findings and published in a peer reviewed journal of medicine. Findings will be presented in at least one local conference.

3.12 Limitations of the Study

It was difficult to recruit men in the study and therefore a comparison between fathers and mothers could not be done. Fathers did not feel comfortable attending interviews to talk about grief.

CHAPTER FOUR

4 RESULTS

4.1 Introduction

The researcher enrolled Seventy-three (73) parents who had undergone perinatal loss during the study period and they completed bereavement care experiences questionnaires. 10 of these parents participated in parent/couple IDIs while 7 participated in a Focus Group Discussion. 1 FGD, 10 IDIs were conducted with affected parents to understand their experiences while receiving bereavement care in KNH. The researcher also had 65 healthcare workers providing services to these bereaved parents taking part in the study and completed questionnaires to assess their adherence to best bereavement care practices. 3 Key informant interviews were conducted to gain insight on existing structures for bereavement care provision.

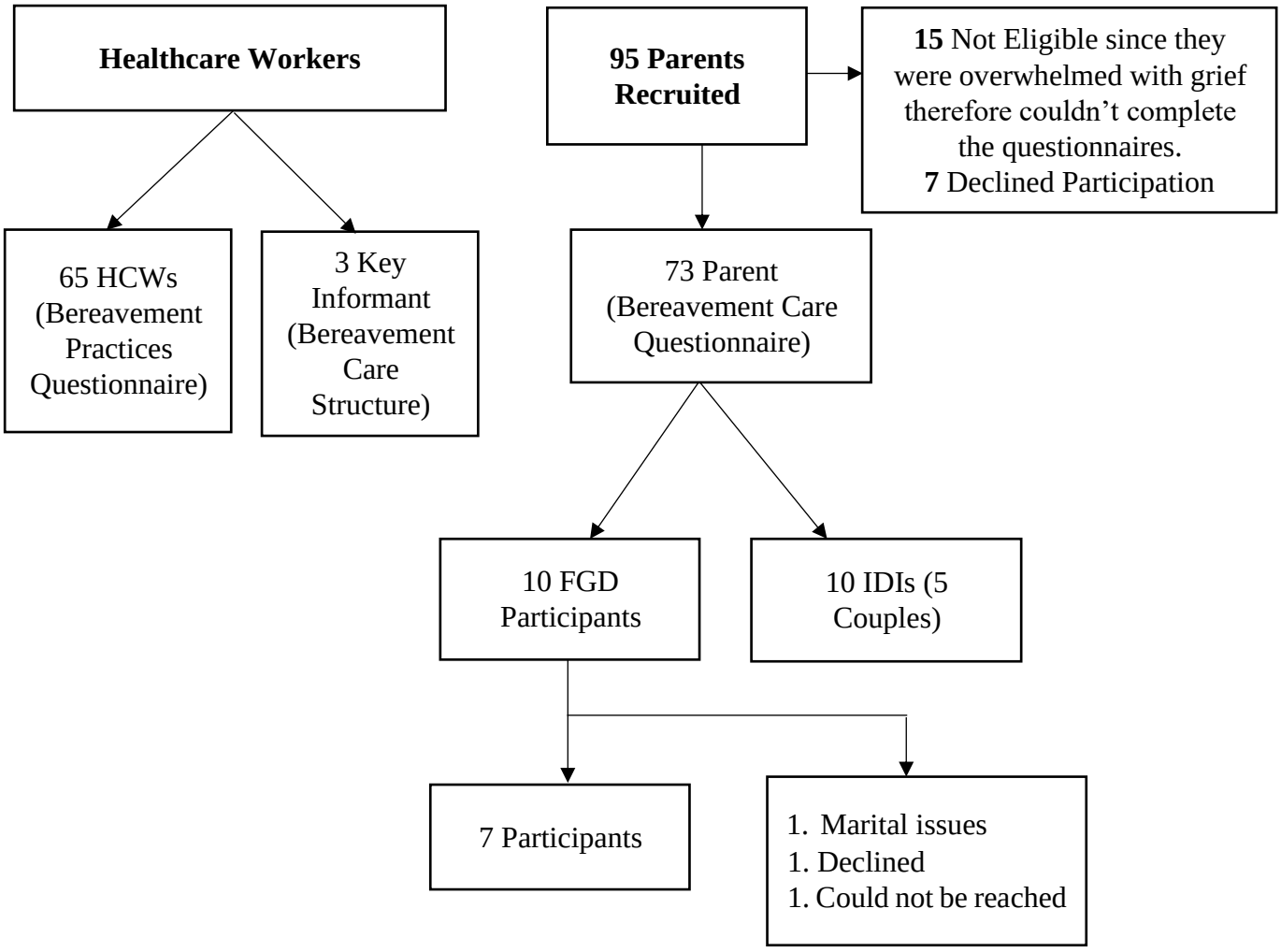

Figure 2. Recruitment Schema of parents with perinatal loss in KNH and health care workers

4.2 Characteristics of parents with perinatal loss in KNH

4.2.1 Socio-demographic characteristics of parents with perinatal loss in KNH

There were only 2 (3%) males while 71 (97%) were female who had median age of 29 years. 75% of the participants had post primary education and nearly half 36 (49%) were employed. Majority of them 64 (88%) were married.

Table 2. Sociodemographic characteristics of parents with perinatal loss in KNH, 2020

Socio-demographic characteristics of parents N=73	
Characteristic	**n (%) or median (IQR)**
Age, median (IQR)	29 (25-33)
Gender	
Female	71 (97)
Male	2 (3)
Marital status	
Married	64 (88)
Single	9 (12)
Education level	
Primary	18 (25)
Secondary	42 (57)
Tertiary	13 (18)
Religion	
Christian	71 (97)
Muslim	2 (3)
Profession	
Employed	36 (49)
Self employed	15 (21)
Unemployed	22 (30)

4.2.2 Obstetric characteristics of women with perinatal loss in KNH

The median parity of mothers who were going through perinatal loss was 2 (1-3). While only less than a quarter of the mothers 15 (21%) had preconception care, nearly all i.e. 68 (96%) attended ANC with a median number of visits 4 (3-5), only less than half 36% were receiving ANC services at KNH. About one third 24 (34%) of the mothers experienced complications in pregnancy with hypertensive disease in pregnancy accounting for more than half, (54%) of the complications. Majority of the mother went through perinatal loss in the last trimester, at a median 31 (30-36) weeks gestation and delivered infants whose median birth weight was 1720 grams (1400-2200 grams).

Table 3. Obstetric Characteristics of women with perinatal Loss in KNH 2020

Obstetric characteristics N=71	
Characteristic	**n (%) or median (IQR)**
Parity, median (IQR)	2 (1-3)
Preconception care	15 (21)
Attended ANC	68 (96)
No. of ANC visits, median (IQR)	4 (3-5)
ANC Visits at KNH	26 (37)
Pregnancy complications	24 (34) *
Gestation at delivery, median (IQR)	31 (30-36)
Birth weight, median (IQR)	1720 (1400-2200)

* 13 (54%) Hypertensive disease in pregnancy, 4 (17%), APH, 7 (39%) Others

4.3 Parents' bereavement care experiences of parents: quantitative findings

Most of the parents 66 (90%) felt that the bad news was delivered with sensitivity while 62 (85%) felt that the information delivered was clear and unambiguous. Regarding privacy during the breaking of bad news, slightly less than a third felt that privacy was not taken care of, with 51 (70%) acknowledging privacy. In addition, 55 (75%) felt that they had an opportunity to ask questions and 51 (70%) felt they had enough time to process the information about the loss. However, only half 27 (51%) had a chance to have a partner or another person present when they were receiving the bad news and only 19(26%) were introduced to their care team. **Overall, 57% of parents reported having a positive experience on how the bad news was broken to them.**

Table 4. Proportions of parents who had a positive experience on how bad news was broken to them in KNH, 2020

Experience on information delivered	**N=73 n(%)**
Information delivered with sensitivity	66 (90)
Clear, Precise and Unambiguous information	62 (85)
Information given in private space	51 (70)
Open to asking questions	55 (75)
Parent blamed for loss of child	8 (11)
Enough time given to process outcome	51 (70)
Allowed an option of having partner or another person present	37 (51)
Introduction of care team	19 (26)
Written information and contact information given	24 (33)
Cumulative	**57%**

4.3.1 Experiences during labour and delivery

There were variations on the different aspects of bereavement care during labour and delivery. Majority of the parents 66 (90%) felt they were treated with respect and 59 (81%) felt that they were closely monitored during labour just like other mothers. On other aspects such as being given enough time with the baby, just about half 36 (49%) had a positive experience while only 21 (29%) received support to hold the baby. Regarding facilitation to keep memories of the baby, only 11 (15%) were offered that chance. On family inclusion, only 25 (34%) felt it was done in an appropriate manner with just about a quarter of parents 19 (26%) feeling that their faith and cultural beliefs were respected.

Overall, 41% of parents had positive bereavement care experiences during labour and delivery.

Table 5. Experiences during labor and deliver in parents who had perinatal loss in KNH, 2020

Experience during labour and delivery	N=73 n(%)
Respectful care given	66 (90)
Close monitoring offered like any other mother in labour	59 (81)
Given enough time with baby after birth	36 (49)
Support to care for and hold my baby after delivery	21 (29)
Offered a chance to have footprints, photos or other mementos	11 (15)
Appropriate inclusion of family members	25 (34)
Faith and cultural beliefs respected	19 (26)
Pain free labour offered	5 (7)
Cumulative	**41%**

4.3.3 Experiences during postnatal care

During postnatal care, soon after childbirth, only 21 (29%) were offered bereavement counseling and a similar percentage were offered private space to mourn which was defined as a secluded area away from other patients. About a quarter of the parents 19 (26%) had access to a religious leader of their faith in the facility. On discharge from hospital, 44 (61%) were referred for postnatal care. Less than half 27 (37%) and 27 (38%) had a chance to discuss future pregnancies and funeral options respectively. It was noted that only 30 (41%) received lactation suppression care in terms of medication or conservative measures yet it is expected to be standard of care for such mothers.

Overall, 35% of parents had a positive bereavement care experience during the postnatal period.

Table 6. Experiences during postnatal care in parents who had perinatal loss in KNH, 2020

Experience during postnatal care	N=73 n (%)
Immediate care after child birth	
Bereavement counselling offered	21 (29)
Religious leader of my faith invited	19 (26)
Private room to mourn given	21 (29)
Lactation suppression done	30 (41)
On discharge from hospital	
*Referred to postnatal clinic and psychotherapy clinic	44 (61)
*Discussed future pregnancies	27 (37)
*Funeral option discussed	27 (38)
**Post-mortem services discussed	12 (17)
Cumulative	**35%**
*N=72, One participant did not respond, was emotionally unable **N=70, Three participants did not respond, were emotionally unable	

4.4 Affected parent experiences – qualitative findings

Majority of the clients felt that the HCWs were to blame for their loss because of delays in attending to mothers who had been referred from facilities outside KNH for a complicated condition in pregnancy or were receiving services within the hospital but had condition that they felt warranted emergency care. Once they had lost the baby, they seemed more resigned to fate - "it has already happened." Because of that feeling, some parents seemed to have an underlying negative perception towards the healthcare providers attending to them. From the Focused Group Discussion and In-depth-Interview the following themes were generated.

- **Lack of effective communication from the Healthcare providers regarding the loss.**

Mothers/parents criticized how the bad news was broken to them. In some instances, mothers reported having to ask the HCWs about the baby hours after delivery as the HCWs did not voluntarily give information about the loss.

"Again communication should be improved, at least let it not be the patient finding out from the staff." FGD, Participant 2

There were instances where mothers overhead HCWs discussing the baby's death amongst themselves without first breaking the news to her.

"She did not tell me anything, she just took the baby and when I was still there lying, I heard them saying that the baby is already dead, I really felt bad." Mother, IDI 2

There were mothers who felt that timing of delivering information was at a moment when nothing seemed to make sense. There was no assessment if they were in a state to understand what was being said to them except the HCW had an obligation to fulfill.

"When I regained consciousness, they did not take time to find out if I had regained my memory. Actually, I was very confused and they were just using big terminology that I did not understand, they gave me a lot of papers to sign." FGD, Participant 3

Some mothers felt that the information from HCWs was rather bland yet they would have appreciated at least some empathy to ease their pain and even an explanation of how they are going to handle the dead baby and what the mother should expect to happen afterwards.

"***They should sit you down and talk to you nicely, not just telling you that the baby has passed on and they start wrapping as you are watching they should talk to you in a nice way and take the baby away and wrap when you are not watching. They should talk to you in such a way that you feel better."*** FGD, Participant 5

More often than not, news regarding the loss was broken to the mother by the HCW and the mother would be left with the responsibility of informing the father of the child or other family members. The fathers complained that they didn't get communication from the hospital staff.

"I wasn't allowed to stay with my wife. When she went for the scan, the hospital didn't call me to give me feedback about her results, its only when I called my wife, that I found out that our baby

was no more. I stopped what I was doing and came to the hospital to see her, on arrival no one explained to me what had happened." Father, IDI 7

- **Lack of counseling services**

Most of the parents would have appreciated if counseling was provided to help them deal with the painful experience of child loss. In most cases, mothers or their partners did not receive counselling. Among some families, the male partners felt that the women were too emotional, spending a lot of time crying – grief counselling provision to both may help understand that each individual will go through the process in their own unique way and also provide the much-needed emotional support.

"My wife is still crying a lot, weeks after losing the baby; I would like you to talk to her for long will she cry?" Father 1, IDI

Men also have to take on the role of providing support to their grieving wives yet they equally need the support.

"So, I am trying to encourage her; just that because I can't be stressed and she is also stressed up, I just try to encourage her. I am in pain because it's the second loss but there is nothing I can do. "

Father 9, IDI

Sometimes while women seem withdrawn and tend to want to be strong after going through loss, they may easily be going into depression. This may be eased if counseling in enhanced during the mourning period right from the hospital.

"When she came back to the clinic, the doctor told her that she is at risk of getting depressed but no counselling was done, nothing at all. Since then I have been supporting her to see if she can cope" Father, IDI 6

The women who had experienced perinatal loss strongly recommended that counseling is a priority for someone going through perinatal loss because it is a difficult moment.

"Such women should get more counseling, and as the hospital, they should improve on their services, if the baby has died, call the mother aside and explain to them nicely." FGD, Participant 1

Providing information on future pregnancies is important as part of counseling information.

Parents, including both mothers and fathers had critical questions regarding future pregnancies.

"I think my only question is, my wife has had 3 caesarean sections, and lost 2 babies, is there a chance she can still have another baby?" IDI, Father 9

"What I wanted to say is that, for example in my case, how long I will take like how many months can I stay before getting pregnant again." IDI, Mother 2

- **Lack of family involvement in bereavement care plan**

Fathers were hardly included in the bereavement care procedures; some did not have a chance to see their babies. This is because the fathers were not allowed access to labour ward. Some would have preferred a chance to see the baby but this was not provided.

"I would have loved to see the baby but they did not allow me into the labour ward." Father IDI 7

In some cases, the information regarding the loss may was not comprehended and resulted in straining the relationship as the man may blamed the wife for the outcome. This happened since the women are the ones who received the information and passed it on to the husbands. Passing information and how it is received is dependent on a number of factors and sometimes getting information from the primary source i.e. the healthcare worker might be a good option.

"My husband blames me for the loss and he has even asked that I leave and go upcountry, he says that I should have gotten the rhesus injection in good time to avoid losing the baby. I don't know what to do; I don't even want to talk about the loss, I wish he was there when the doctor explained" FGD participant who dropped out.

In cases where family members were included, the affected women felt it was useful to their mourning process.

"There is a HCW who was helpful, she followed up on my progress and counseled me, talked to my mother and my boyfriend." FGD, Participant 1

- **Lack of conducive environment for a grieving parent**

Women were very uncomfortable being in shared spaces with women who had babies while they were receiving postnatal care. They said it was a difficult and traumatizing experience as it triggered painful emotions of their loss.

"There is nothing as tough as being in the same ward with mothers who are breastfeeding, yet you came with a pregnancy and you are going home empty handed, it is hard." FGD, Participant 2

"It could have been good if they could separate those with babies from those that don't have babies, even in the clinic, you may find you have gone to the clinic and meet those you knew before and they have babies, yet you have not received any counseling, it's very traumatizing. " FGD, Participant 4

"It was very stressful being in the ward, other mums are breastfeeding, you see others going to deliver and coming back with babies, it's a painful feeling you are not aware of, I really wanted to leave the hospital as soon as possible" FGD, Participant 5

- **Impact of Patients' religious beliefs and culture on bereavement experiences**

Often people spiritual and cultural beliefs regarding death impacts their bereavement process and some parents relied on their faith to cope with loss despite their loss being received negatively by those around them. Other parents paid attention to their cultural beliefs: linking their loss to some cultural disobedience.

"People started criticizing me saying that our church worships the devil, because, when I lost my child, I did not cry instead I gave out the offering for that child, so I could not cry because I knew my child has gone to a safer place. I would have loved for my son to have been prayed for in the hospital." IDI, Father 3

"In our family, my older sister and my mother have been through caesarean section. Since she (My sister) gave birth at our home and her baby was a boy, she had to bury him at her husband's home. According to our tradition there was some cattle that was to be brought home by the father of the baby so as cleanse the spirit of caesarean section. She has lost 2 more babies all delivered through caesarean section. They have still not brought dowry, I think my loss is linked to this, and we had planned to go home." IDI, Mother 4

"I can't really say anything much about the loss, our faith has helped us cope with the loss and we believe God will give us another child." IDI, Father 6

4.5 HCW Characteristics and adherence to bereavement care practices

4.5.1 Healthcare worker characteristics

Majority of the HCWs providing bereavement care were fairly young at a median age of 33 (30-36) and most were female 43 (66%). More than half, 41 (63%) were nurses and only 11(17%) had received bereavement care training. The median period of time working in the unit was 4 (2-7) years and 9 (14%) had gone through personal child loss.

Table 7. Socio-demographic Characteristics of health care workers attending to parents with perinatal loss in KNH, 2020

Characteristic	N=65 n (%) median (IQR)
Age, median (IQR)	33 (30-36)
Gender	
Male	22 (34)
Female	43 (66)
Profession	
Nurses	41 (63)
Doctors	24 (37)
Years of experience in unit, median (IQR)	4 (2-7)
Bereavement care training	11 (17)
Religion	
Christian	57 (87)
Muslim	5 (8)
Missing	3 (5)
Personal child loss	9 (14)

5.1.1 HCW adherence to best bereavement care practices

On adherence to bereavement care practices, 60 (92%) of HCWs request an obstetric ultrasound to confirm IUFD.

During breaking of bad news, a minimal number 4(6%) of HCWs allow the next of kin to be present during breaking of bad news, only 11 (17%) use a separate room and 5 (8%) ensure a counselor is present.

During labour and delivery, Majority of HCWs 54 (83%) reported monitoring maternal vital signs regularly for women with IUFD; only 5 (8%) of HCWs reported offering pain free labour for women with IUFD and 4 (6%) allow them to labour in a separate room. After delivery of macerated still birth (MSB) or fresh still birth (FSB) 59 (91%) HCWs clean and wrap the baby, 9 (14%) offer mementos and 41 (63%) allow the mother to hold the baby as long as she wants. Less than half, 26 (40%) of HCWs consider patients' spiritual and cultural beliefs when offering bereavement care.

During postnatal care, almost all, 61 (94%) of HCWs provide medication to suppress lactation and 59 (91%) allow parents to ask questions regarding the loss. Very few providers, 10 (15%) discuss

funeral options with parents while 13 (20%) discuss postmortem. More than half 40 (62%) of the providers interviewed advised parents on seeking postnatal care services. On their part, 75% of HCWs were emotionally affected when caring for patients going through perinatal loss but only 2 (3%) sought debriefing services from a counselor.

Table 8. Adherence to best bereavement care practices by Health Care workers attending to Parents with Perinatal Loss in KNH, 2020

Bereavement care practices	**N=65 n (%)**
Requested an Obstetric Ultrasound (U/S) to be performed to confirm an IUFD	60(92)
Allowed the next of kin to be present during breaking bad news	4 (6)
Use of a separate room for breaking the bad news	11(17)
Allowed a religious leader to be present in case the patient requests for one	33(51)
Ensured presence of a counselor during breaking of bad news.	5 (8)
Offered pain free labour for those with IUFD	5 (8)
Monitored maternal vital signs and labor in women with IUFD as frequent as for those with Live Intrauterine Pregnancies.	54(83)
After delivery of FSB or MSB: a) Cleaned and wrapped the baby b) Offered mementos e.g. footprints, handprints, photos c) Allowed parents to hold the baby for as long as they want	 59(91) 9 (14) 41(63)
Took into consideration parents spiritual and cultural believes regarding loss.	26(40)
Allowed them to labor in a separate room from the ones with live intrauterine pregnancies	4 (6)
Provided medication to suppress the lactation.	61(94)
Discussed funeral options with parents	10(15)
Allowed Parents to ask questions about the loss.	59(91)
Advised on Postnatal care and psychotherapy after discharge	40(62)
Advised on perinatal postmortem.	13(20)
Emotionally affected when attending to parents with perinatal loss	49(75)
Debriefing sessions sought from the unit grief counselor for those who are emotionally affected	2 (3)

5.2 Bereavement care structure at KNH

The bereavement care structure was deficient in most aspects assessed, with the unit only having access to an ultrasound machine. The multidisciplinary team required to take care of parents going

through loss was not complete, no protocols for bereavement care or training modules, no private spaces for labour and postnatal care. The unit did not have counseling rooms or provision for pain free labour, tools for taking mementos or any special considerations for mothers attending postnatal clinics.

Table 9. Structure in Place for bereavement care provision after Perinatal Loss in KNH, 2020

Bereavement structure at KNH	
Multidisciplinary Team:	
Obstetrician	**YES**
Neonatologist	**YES**
Primary Nurse	**YES**
Grief Counsellor	NO
Religious Leaders	NO
Counselling room in labour ward and each of the postnatal ward	NO
Bereavement care Protocol	NO
Training module for healthcare workers on bereavement care	NO
Ultrasound for diagnosis of IUFD in Labour Ward	**YES**
Private Labour room for those with IUFD	NO
Medication to ensure pain free labour	NO
Maternity Unit Laboratory that can-do tests round the clock	NO
Private Postnatal room for those who have had a loss	NO
Tools to take mementos:	NO
Camera	NO
Ink for palm print or footprint	NO
Birth card for the baby	NO
Special consideration for those attending postnatal clinic after loss	NO
Bereavement care sign	NO

5.3 Key informant (Healthcare workers) views on bereavement care and structure in KNH.

Key informants were aware that parents tend to blame HCWs for the loss of a child.

"Whenever they have a bad outcome, they tend to blame it on our "poor" management." KII 2.

The following themes were generated after the key informants' interviews.

- **No formal bereavement care training**

Key informants were quite clear that that there is no formal training on bereavement care for HCWs that provide bereavement care for families going through perinatal loss.

To standardize care, I think, one maybe is the training, on job training of health care providers on the same (bereavement care) so that they know it is important and maybe having in place formal structure on how to refer a woman or come see the women especially when they call on you whenever there is a loss … like I told you the issue of still birth and early neonatal death, that sort of thing is fairly rampant so a lot of people don't give it attention it deserves. I think training, sensitization and having a formal referral process that each woman has to undergo would really help." KII 1

"I am not aware of any training modules in place, I think it's mainly based on the experience you have, how you handled the first one and the next one." KII 3

- **Unavailability of counseling in the unit**

Healthcare workers are cognizant of the fact that perinatal loss is a devastating experience for women and their families. HCWs are not left out whenever they have a bad outcome since their goal is to have a successful delivery, they too are affected. While acknowledging that counseling is a basic need for the women and families that have gone through perinatal loss, they note that they are not able to offer counseling services. They are few counselors in the hospital and they are not located within the unit.

"I must commend the institution where the case warrants for example a woman has been trying for a baby and they end up losing, they do put a lot of effort, to have the woman counselled, have

families conferences to discuss so it's not all doom and gloom in a few selected cases that I think the teams at KNH do go out of their way to have sorted out." KII 1

"I feel like if I had a good number of counsellors in the department, where the counsellors would have ample time with the parents, take them through counselling and even follow up maybe in 2 weeks or a month; this would make the situation better." KII 2

"There is need to offer more psychosocial support to these mothers and families" KII 3

Another aspect of care that is important is counseling is follow up care once the women have been discharged from hospital. HCWs recommend that this could be done through support groups.

- **Lack of follow up services**

While during hospital stay the women may have access to some services, there is no clear laid down procedures regarding follow up once they leave hospital. There are suggestions to have some follow up counseling and as possible a support group.

"I look forward to the day we can offer follow up care and even therapy groups to support these women" KII 2

*"**To be very honest, I feel there is a gap as in a mother loses a baby, doesn't undergo counselling, then we discharge this mother and we don't do any follow up plus most of the time, we barely involve the family."*** KII 2

- **Lack of adequate Healthcare providers in the unit**

Healthcare workers may want to offer bereavement care support but the number of patients they are required to serve in general are too many to be able to give attention to those that are going through perinatal loss. A lot of time they are mistaken for hiding behind these tasks, other times they keep themselves busy just to avoid the whole bereavement care process since its emotionally draining.

"The hospital is overwhelmed, there is overcrowding and it is something we must talk about at both government and county levels that we need to have many maternity units that are able to function and handle the kind of cases we handle." KII 3

"Labour ward is quite busy and the nurse patient ratio is not favorable, sometimes the midwife may not be able to give appropriate counselling service." KII 2

- **Lack of a standardized bereavement care protocol that should also address the cultural and religious diversity.**

Healthcare workers acknowledge that religious and cultural beliefs influence perception of death and to a great extent the woman and family needs for bereavement care. It is therefore an important aspect to keep in mind when developing bereavement care procedures.

"People from certain culture really value the dead. Mothers from such cultures will be like, "I really want my husband to view the body." There are other cultures where the mother loses the baby or has a stillbirth and they are like, "sister, just do what you usually do, when my husband comes, I will take him through. Healthcare workers should incorporate these beliefs when attending to the parents. KII 2

"We have a variety of religion in our country; for me in terms of loss, I would obviously prefer to deal with the Muslim community because you find their attitude towards loss is that, it is God's will, they don't question much. They tend to accept more easily than parents of other faiths. "KII 3

CHAPTER FIVE

6 DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

6.1 Discussion

The main findings from this study were: The median age of parents who had PL was 29 years, 75% had attained post primary education, hypertensive diseases (54%) were cited as most common complication that led to PL while the median birth weight of babies was 1720grams. As per the experiences of the affected parents the following themes were generated: poor communication, lack of counselling services, family involvement and poor integration of patients' own beliefs and culture during bereavement care provision. In terms of adherence to best bereavement care practices it was established that the next of kin was barely involved, funeral options and perinatal postmortem were hardly discussed and these women weren't offered pain free labor for those who already had intrauterine fetal demise. There was poor structure in KNH to support bereavement care provision this was evidenced by lack of formal bereavement care training, bereavement care protocols, bereavement care sign, separate rooms for counselling, labor and postnatal care provision. Healthcare workers also did not have tools to take momentos.

In designing this study, the researcher's main intention was to gain a better understanding of the bereavement care offered for parents who have had a stillbirth at Kenyatta National Hospital and offer insights for improvement of this care to better the experience of such parents. From the data, perinatal loss was commonest between the second and third decade of life, as most of the study participants were aged 25-33 years. Moreover, married women, especially those with a secondary level of education were at a higher probability of delivering a stillbirth, as most of the participants exhibited this socio-demographic profile. Finally, even though formal statistical testing was not done, perinatal loss was higher among parents with a form of employment. Similar findings have been reported in Africa. In Mpumalanga in South Africa, for instance, the incidence of macerated and fresh stillbirth and early neonatal death was high among nulliparous women aged 20-34 years, with a comorbidity

such as HIV (58). In Tororo Uganda, the median age of women with a perinatal loss was estimated to be 25 years (20-30) (59), while socio-demographic factors such as youth (20-34 years) was associated with a higher risk of perinatal mortality in Ethiopia (60). During admission, initial screening of patients should identify such high-risk groups for initiation of measures that can lower the risk of loss or ease the delivery process.

From the data, the reproductive characteristics of women with a stillbirth delivery mirrored those of women from Southern and East Africa. As in Uganda (59), for instance, perinatal loss was high among women with pregnancy complications such as antepartum hemorrhage (APH) and hypertension. Moreover, perinatal loss seemed to be higher when women did not receive pre conception care and had attended less than the recommended minimum ANC contacts (8) by the World health organization (61). In the presence of complications such as APH, CKD, and hypertension, the lack of such vital services can increase the risk of neonatal deaths, as a strong positive association between ANC attendance and neonatal death has been demonstrated in sub-Saharan Africa. In a systematic review by Tekelab et al. (62) increasing ANC attendance by one unit lowered neonatal deaths by 39%. In another study by Doku and Neupane meeting the recommended ANC attendance threshold by the WHO lowered the risk of neonatal deaths by approximately 55% (63). Therefore, to meet the recommendations of the Millenium Development Goal 4 on the reduction of neonatal and perinatal mortality (64), sensitization campaigns and health programs that can increase access to ANC and pre-conception health services are warranted at KNH.

From the accounts of patients, the delivery of information on stillbirths was optimal, as most parents were satisfied with the clarity and ambiguity of information offered, and felt that information about the death of children was offered with sensitivity and in a private manner. However, even though most spouses were granted access to grieving partners to offer psychological support during information dissemination, handling of parents by health care workers was sub-optimal, as a majority did not provide contacts for follow up and handled parents in a manner that made them feel responsible for

the loss of their children. Similar findings were reported in an Evidence-based study in Australia (33), in which grieving parents were dissatisfied with the manner in which information dissemination was handled when it was time to see or handle their babies. In another systematic review by Ellis et al. (34), the divide between parents and health care providers and system barriers such as lack of private areas for grieving complicated the grieving process for a majority of parents. Through training on bereavement care, health care providers can be taught on how to interact better with such vulnerable women to improve coping strategies. Increasing bonding time and the provision of a grief counsellor during the dissemination of information can also ease the burden on women, as their lack of in delivery units was a primary concern of most grieving parents during our Focus Group Discussions (FGDs).

During labour and delivery, only four out of ten parents received positive bereavement care after a perinatal loss, which was in line with the findings of Aiyelaagbe et al. in Nigeria (65). While a majority of parents were handled with respect and without discrimination during this trying time, a majority were less likely to receive pain-free labour options, even though it is a recommended protocol for easing bereavement pain (66). Moreover, provision of mementos, engaging spouses in delivery, and integrating cultural beliefs of parents with clinical guidelines for bereavement care were sub-optimal, as less than 30% of women who delivered a stillbirth at the Kenyatta National Hospital were accorded this service. Regrettably, this seems to be the trend globally, as similar findings are reported (33,34).

During the postnatal period, bereavement care immediately after a stillbirth delivery for close to 70% of women at the Kenyatta National Hospital was suboptimal. While referrals for psychotherapy were instituted and post-natal evaluations recommended to affected women approximately 60% of the time, bereavement counselling was almost non-existent during the time of need for parents. Moreover, even though the engagement of religious leaders in bereavement counselling has been found to lower the incidence of depression and other psychological deficits statistically (67), less than three out of ten grieving parents had access to the service at the Kenyatta National Hospital. This poses a challenge for a majority, as parents depend solely on the guidance of health care workers, who have been found

to struggle with stillbirth deliveries as much as parents do (68). Thus, policy changes on bereavement, which include sensitization of health care workers, institution of counselling and religious support systems, and elucidation of funeral or postmortem options are warranted, as the services were lacking.

At the Kenyatta National Hospital reproductive unit, standard bereavement care protocols such as ultrasound examinations, frequent monitoring of maternal vital signs, provision of medicines for lactation suppression, and proper care, and handling of babies were in force. However, through our interactions with health care workers, it was sad to note that only 10% of health care providers strived to offer pain free labour options, while less than 8% debriefed and sought the services of a grief counsellor while disseminating information. Funeral and post mortem options were hardly discussed, while labour and delivery was not discrete, probably due to system failures such as understaffing and the lack of a comprehensive bereavement care protocol for grieving parents, as was evident from our data. While grieving parents had access to obstetricians, neonatologists, and nurses, the reproductive unit of the Kenyatta National Hospital lacked grief counsellors and religious leaders. Moreover, the bereavement standard lacks provisions for mementos such as pictures and footprints and a private room for grieving parents due to lack of equipment and infrastructure. Addressing such limitations can improve bereavement care, better the quality of life of grieving parents, and improve their quality of life after the loss of a child.

6.2 Conclusions

From the study, bereavement care experience of affected parents after perinatal loss in KNH is suboptimal. It was also noted that healthcare providers are not adhering to the recommended best bereavement care practices when attending to parents who have experienced perinatal loss in KNH. The bereavement care provision structure was also noted to be in a deplorable state.

6.3 Recommendations

The framework for bereavement care needs to be improved looking at the 3 components: structure, process and outcome. The bereavement care experience of affected parents after perinatal loss in KNH should be improved by encouraging the healthcare workers to adhere to the recommended best bereavement care practices when attending to this parents. These can be realized by: Developing guidelines for bereavement care, providing structure and training for bereavement care and also encouraging male parent involvement in bereavement care.

6.4 Source of Funding

This study was self-sponsored

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APPENDICES

Appendix 1a: PARTICIPANT INFORMATION AND CONSENT FORM (Affected parents)

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PARTICIPANT INFORMATION AND CONSENT FORM

FOR ENROLLMENT IN THE STUDY

Title of Study: FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' PERSPECTIVE AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL

Principal Investigator\and institutional affiliation: Dr Lydia Wanja Njiru a master's student in the department of obstetrics and Gynecology ,University Of Nairobi.

Spervisors and institutional affiliation:

1. Dr.Rose Kosgei-Dept of Obs & Gyn ,UON,
2. Dr.Wanyoike Gichuhi- Dept of Obs & Gyn UON,
3. Dr.Sabina Wakasiaka-School of Nursing Sciences, UON
4. ,Prof. Anne Obondo-Dept. of Psychiatry, UON

Introduction:

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research: i) Your decision to participate is entirely voluntary ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue? YES / NO
This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No.P703/08/2019

WHAT IS THIS STUDY ABOUT?
The researchers listed above are interviewing individuals who have experienced perinatal loss in KNH during the study period. The purpose of the interview is to find out the bereavement care experiences of the affected parents attended in KNH. Participants in this research study will be asked questions about their bereavement care experiences.
There will be approximately 73 participants in this study purposively chosen. We are asking for your consent to consider participating in this study.

WHAT WILL HAPPEN IF YOU DECIDE TO BE IN THIS RESEARCH STUDY?
If you agree to participate in this study, the following things will happen:
You will be interviewed by a trained interviewer in a private area where you feel comfortable answering questions. The interview will last approximately 30 minutes. The interview will cover topics such as Breaking of bad news, antepartum intrapartum and postpartum best bereavement care practices.
After the interview has finished**,** any participant who experiences any psychological distress will be referred to patient support services unit for psychological counselling.
We will ask for a telephone number where we can contact you if necessary. If you agree to provide your contact information, it will be used only by people working for this study and will never be shared with others. The reasons why we may need to contact you include: to remind you of the i-depth interview and focused group discussion session.

ARE THERE ANY RISKS, HARMS DISCOMFORTS ASSOCIATED WITH THIS STUDY?
Medical research has the potential to introduce psychological, social, emotional and physical risks. Effort should always be put in place to minimize the risks. One potential risk of being in the study is loss of privacy. We will keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.
Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.
We will do everything we can to ensure that this interview is done in private. Furthermore, all study staff and interviewers are professionals with special training in these examinations/interviews, since, we understand that talking about your loss may be stressful.

ARE THERE ANY BENEFITS BEING IN THIS STUDY?
The information you provide will help us better understand the needs of parents when they experience perinatal loss. This information is a contribution to science, body of knowledge and therefore inform in policy of bereavement care practices.

WILL BEING IN THIS STUDY COST YOU ANYTHING?
NO

WILL YOU GET REFUND FOR ANY MONEY SPENT AS PART OF THIS STUDY?

NO

WHAT IF YOU HAVE QUESTIONS IN FUTURE?

If you have further questions or concerns about participating in this study, please call or send a text message to the study staff at the number provided at the bottom of this page.

For more information about your rights as a research participant you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. 2726300 Ext. 44102 email uonknh_erc@uonbi.ac.ke.

WHAT ARE YOUR OTHER CHOICES?

Your decision to participate in research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of any benefits.

CONSENT FORM (STATEMENT OF CONSENT)

Participant's statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential.

By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study:	**Yes**	**No**
I agree to have (define specimen) preserved for later study:	Yes	No
I agree to provide contact information for follow-up:	Yes	No

Participant printed name: _____

Participant signature / Thumb stamp _____ Date _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher 's Name: _____ **Date**: _____

Signature _____

Role in the study: _____ *[i.e. study staff who explained informed consent form.]*

For more information contact _____ at _____ from _____ to _____

Witness Printed Name (*If witness is necessary, A witness is a person mutually acceptable to both the researcher and participant*)

Name _____ Contact information _____

Signature /Thumb stamp: _____ Date; _____

Appendix 1b: PARTICIPANT INFORMATION AND CONSENT FORM (Healthcare providers)

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PARTICIPANT INFORMATION AND CONSENT FORM

FOR ENROLLMENT IN THE STUDY

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Principal Investigator\and institutional affiliation: Dr Lydia Wanja Njiru a master's student in the department of obstetrics and Gynecology**,**University Of Nairobi.

Supervisors and institutional affiliation:

1. Dr. Rose Kosgei-Dept of Obs & Gyn, UON
2. Dr. Wanyoike Gichuhi- Dept of Obs & Gyn UON
3. Dr. Sabina Wakasiaka-School of Nursing Sciences, UON
4. Prof. Anne Obondo-Dept. of Psychiatry, UON

Introduction:

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research: i) Your decision to participate is entirely voluntary ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue? YES / NO

This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No. P703/08/2019

WHAT IS THIS STUDY ABOUT?

The researchers listed above are interviewing individuals who have experienced perinatal loss in KNH during the study period and healthcare workers who attend to these parents in the maternity unit-labour ward. The purpose of the interview is to find out the bereavement care experiences of the affected parents who were attended to in KNH. It will also inform us of healthcare workers adherence to best bereavement care practices. Affected parents Participants in this research study will be asked questions about their bereavement care experiences while Healthcare workers will also inform us of their experiences and challenges while offering this service.

There will be approximately 73 affected parents participants and 65 healthcare providers in this study purposively chosen. We are asking for your consent to consider participating in this study.

WHAT WILL HAPPEN IF YOU DECIDE TO BE IN THIS RESEARCH STUDY?

If you agree to participate in this study, the following things will happen:

You will be interviewed by a trained interviewer in a private area where you feel comfortable answering questions. The interview will last approximately 30 minutes. The interview will cover topics such as Breaking of bad news, antepartum intrapartum and postpartum best bereavement care practices.

We will ask for a telephone number where we can contact you if necessary. If you agree to provide your contact information, it will be used only by people working for this study and will never be shared with others. The reasons why we may need to contact you include: to remind you of the key informant interview.

ARE THERE ANY RISKS, HARMS DISCOMFORTS ASSOCIATED WITH THIS STUDY?

Medical research has the potential to introduce psychological, social, emotional, and physical risks. Effort should always be put in place to minimize the risks. One potential risk of being in the study is loss of privacy. We will keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.

We will do everything we can to ensure that this is interview is done in private.

ARE THERE ANY BENEFITS BEING IN THIS STUDY?

The information you provide will help us better understand the needs of parents' when they experience perinatal loss, the challenges healthcare providers face when offering this service. This information is a contribution to science, body of knowledge and therefore inform in policy of bereavement care practices.

WILL BEING IN THIS STUDY COST YOU ANYTHING?

NO

WILL YOU GET REFUND FOR ANY MONEY SPENT AS PART OF THIS STUDY?

NO

WHAT IF YOU HAVE QUESTIONS IN FUTURE?

If you have further questions or concerns about participating in this study, please call or send a text message to the study staff at the number provided at the bottom of this page.

For more information about your rights as a research participant you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. 2726300 Ext. 44102 email uonknh_erc@uonbi.ac.ke.

WHAT ARE YOUR OTHER CHOICES?

Your decision to participate in research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of any benefits.

CONSENT FORM (STATEMENT OF CONSENT)

Participant's statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential.

By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study:	**Yes**	**No**
I agree to have (define specimen) preserved for later study:	Yes	No
I agree to provide contact information for follow-up:	Yes	No

Participant printed name: _____

Participant signature / Thumb stamp _____ Date _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher 's Name: _____ **Date**: _____

Signature _____

Role in the study: _____ *[i.e. study staff who explained informed consent form.]*

For more information contact _____ at _____ from _____ to _____

Witness Printed Name (*If witness is necessary, A witness is a person mutually acceptable to both the researcher and participant*)

Name _____ Contact information _____

Signature /Thumb stamp: _____ Date; _____

Appendix 2a: Questionnaire for Affected Parents

FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL

DEMOGRAPHIC DATA

Study number: .....

SECTION A: SOCIODEMOGRAPHIC DATA

1. Age (Years): _____
2. Gender: Male ☐ Female ☐
3. Parity: _____
4. Marital status:
   a) Married ☐
   b) Single ☐

5. Religion
   a) Christian ☐
   b) Muslim ☐
   c) Others ☐

6. Education level
   a) Primary ☐
   b) Secondary ☐
   c) Tertiary ☐
   d) None ☐
7. Profession
   a) Employed ☐
   b) Self-employed☐
   c) Unemployed ☐
8. Did you have any preconception care?
9. Did you attend antenatal clinic?

   Yes ☐

   No ☐

If the answer to question above is yes, indicate:

Number of antenatal visits you attended before delivery: _____
Where were the antenatal visits done? KNH ☐ Others ☐
Any maternal or pregnancy complication you had before loss of the child: Yes ☐ No ☐ If Yes tell us what the complications were:

Kindly indicate gestation at the time of delivery: _____

10. Weight of the baby: _____

11. Sex of the baby: _____
12. Who told you that your baby had died? (Please tick all the relevant people)
    Consultant ☐
    Junior Doctor ☐
    Nurse ☐
    Ultra-sonographer (Person who performs ultrasounds scans) ☐
    Don't Know ☐

SECTION B: ANTEPARTUM CARE

When you were told that your child had died, did you feel that the information was: -

		Yes	No
1	Delivered with sensitivity		
2	Clear, Precise and Unambiguous		
3	Given in private space		
4	Given in a way that you felt you could ask questions		
5	Given is such a way the health care provider blamed me for the loss of my child.		
6	I was given enough time to process my outcome.		
7	I was given an option of having my partner or another person present.		
8	The team to be involved in my care was introduced to me.		
9	I was given written information and contact numbers.		

SECTION C; INTRAPARTUM

During Labor

		Yes	No
1	I was treated with respect (Had sensitive care during labor and delivery.)		
2	The team monitored me closely as frequently as any other mother		
3	I had enough time with my baby after birth.		
4	I had support to hold and care for my baby after delivery		
5	I was asked whether I wanted footprints, photos or other momentos		
6	Other children and family members were included appropriately		
7	I was asked about my faith and Cultural beliefs regarding child Death and my ideas were implemented		
8	Was offered pain free labor***		

SECTION C: POSTNATAL CARE

After death of my child

		Yes	No
1	I was offered a bereavement counsellor/counseling service.		
2	I was offered a religious leader of my faith to stand with me		

3	I was offered a private room to nurse/ mourn my pain		
4	I was given medication to suppress lactation		

On discharge

		Yes	**No**
1	I was offered a chance to attend postnatal clinic and psychotherapy clinic.		
2	My concerns regarding future pregnancies were addressed		
3	Funeral Options were discussed		
4	Was a post-mortem option discussed with you by a member of Staff		

3.During my stay at the hospital, I felt the healthcare provider who really supported me was?

Doctor ☐

Nurse. ☐

Others ☐

What stood out in their service provision?

4.During my period of staying KNH I would say in my own opinion that the quality bereavement care was?

Poor ☐

Good ☐

Excellent ☐

Do you feel that there is something that would have been done different and in a better way? If yes, kindly state.

.....

.....

Appendix 2b Questionnaire for Affected Parents (Kiswahili)

FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL

SEHEMU YA A: DATA YA SOCIODEMOGRAPHIC

1. Umri (Miaka): _____
2. Jinsia: Kike au Kiume
3. Uadilifu: _____
4. Hali ya ndoa:
a) Nimeolewa ☐
b) Kapera☐
5. Dini
a) Mkristo ☐
b) Mwislamu☐
c) Wengine☐
6. Kiwango cha elimu
a) Msingi ☐
b) Sekondari☐
c) Sekondari☐
d) Sikusoma ☐
7. Utaalam
a) Kuajiriwa☐
b) Mfanyibiashara☐
c) Sina kazi☐
8. Je! Ulikuwa na utunzaji wowote wa maoni kabla ya uja uzito? Ndio☐ La ☐
9. Je! Ulihudhuria kliniki ya ujauzito? Ndio ☐Hapana ☐
Ikiwa jibu la swali hapo juu ni ndio, onesha:

Idadi ya ziara za wajawazito ambazo ulihudhuria kabla ya kujifungua: _____
Je! Ziara za wajawazito zilifanyika wapi? KNH au kwingine
Shida yoyote ya mama au mjamzito uliyokuwa nayo kabla ya kumpoteza mtoto: Ndio☐ Hapana☐
Ikiwa Ndio tuambie shida zilikuwa nini:
Onesha uja uzito ulikuwa wa miezi mingapi wakati wa kujifungua: _____
10. Uzito wa mtoto: _____
11. Jinsia ya mtoto: _____
12. Nani alikuambia mtoto wako amekufa? (Tafadhali chapa watu wote)

- Daktari wa akina mama ☐
- Daktari wa watoto ☐
- Muuguzi ☐
- Ultrasonologist (Mtu ambaye hufanya scans za ultrasound) ☐
- Sijui ☐

Ulipoambiwa kwamba mtoto wako amekufa, je! Ulihisi habari hiyo kuwa:

	Ndiyo	La
1. Imesemwa kwa unyeti		
2. Uwazi, Usafi bila tashwishi		
3. Imepewa katika nafasi ya kibinafsi		
4. Unayopewa kwa njia ambayo ulihisi unaweza kuuliza maswali		
5. Ilipewa kwa njia mtoaji wa huduma ya afya alinilaumu kwa upotezaji wa mtoto wangu.		
6. Nilipewa muda wa kutosha kushughulikia matokeo yangu.		
7. Nilipewa chaguo la kuwa na mwenzi wangu au mtu mwingine.		
8.Timu husika katika utunzaji wangu ilijitambulisha.		
9. Nilipewa habari iliyoandikwa na nambari za mawasiliano.		

SEHEMU C; INTRAPARTUM

Wakati wa Kuzaa

1 Nilitendewa kwa heshima (nilikuwa na utunzaji nyeti wakati wa kujifungua.)	Ndio	La
2 Timu iliniangalia mara kwa mara kama mama mwingine yeyote		
3 Nilikuwa na wakati wa kutosha na mtoto wangu baada ya kuzaliwa.		
4 nilikuwa na msaada wa kumshikilia na kumtunza mtoto wangu baada ya kuzaa		
5 Niliulizwa ikiwa ninataka nyayo, picha au mingine mingine		
Watoto wengine na wanafamilia walijumuishwa ipasavyo		
7 Niliulizwa juu ya imani yangu na imani ya kitamaduni kuhusu kifo cha mtoto na maoni yangu yakatekelezwa		
8 Alitolewa maumivu ya bure ya kazi ***		

SEHEMU YA C: KUTENDA KWA KIUME

Baada ya kifo cha mtoto wangu

	Ndiyo	La
1 Nilipewa mshauri wa kufiwa / huduma za ushauri.		
2 Nilipewa kiongozi wa kidini wa imani yangu kusimama pamoja nami		
3 Nilipewa chumba cha kibinafsi kunyonyesha / kuomboleza maumivu yangu		
4 Nilipewa dawa ya kukandamiza kuzaa		

Inatoka

	Ndiyo	La
1 Nilipewa nafasi ya kuhudhuria kliniki ya baada ya kuzaa na kliniki ya pyschotherapy.		
2 Maswala yangu kuhusu ujauzito ujao yalishughulikiwa		
Chaguzi 3 za Mazishi zilijadiliwa		
4 Je! Ilikuwa chaguo la kifo cha kujadiliwa na mjumbe wa Wafanyikazi		

3.Kuwa nilipokaa hospitalini, nilihisi mtoaji wa afya ambaye ananiunga mkono kweli? Daktari

Muuguzi. ☐

Wengine ☐

Je! Nini kilijitokeza katika utoaji wao wa huduma?

4.Kuna kipindi changu cha kukaa KNH ningesema kwa maoni yangu mwenyewe kuwa huduma bora ya kufariki ilikuwa?
Maskini ☐

Mzuri ☐

Bora ☐

Je! Unahisi kuwa kuna kitu ambacho kingefanywa tofauti na kwa njia bora?
Ikiwa ndio, sema kwa fadhili.
……. …….
……. ..... …….
……. …….
…… ..

Appendix 3a: Questionnaire for the Healthcare Professionals

FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED COUPLES' AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL

DEMOGRAPHIC DATA

Study number: .....

1. Age: .....
2. Gender

☐ Female

☐ Male

3. Staff Cadre:

☐Doctor

☐Nurse

4. Experience in unit of practice in years.....
5. Any training in bereavement care?

☐Yes

☐No

6. Personal Child loss experience:

☐Yes

☐No

7. Religion

☐Christian

☐Muslim

☐Buddhist

☐Other: .....

8.Have you attended to any patient who has suffered perinatal loss within the unit?

☐Yes

☐No

If yes kindly fill in the table below, that will inform us of your adherence to best bereavement care practices

BEST BEREAVEMENT CARE PRACTICES

	Yes	No
1. We always request an obstetric Ultrasound (U/S) to confirm an IUFD		
In case we of a perinatal loss we always call the next of kin to be present before breaking the bad news		
3. We have a separate counseling room for breaking the bad news		

4. We have religious leaders of different faiths incase the patient requests for one		
5. We offer pain free labour to those with IUFD.		
We monitor maternal vital signs and labour for those women with IUFD as frequent as for those with live Intrauterine pregnancies		
7. After delivery: FSB or MSB: I Clean the baby and wrap them well I give the mother momentos I allow them to hold the baby for as long as they want.		
After perinatal loss I inquire about the patient's spiritual belief and I don't instill my own beliefs.		
I allow them to labor in a separate room from the ones with live intrauterine pregnancies		
10. I always ensure they get medication to suppress the lactation.		
. We have a counsellor attached to our department that is always present during breaking of bad news		
12. I always give the mother a chance to ask questions about the loss.		
13. I ensure that they get postnatal care and psychotherapy after discharge		
14. I advise them on the importance of postmortem.		
15. I am emotionally affected when dealing with a patient perinatal loss		
16. I discuss funeral options with the parents.		
17. After attending to a patient with perinatal loss we are accorded a debriefing session at the unit by the grief counsellor		

18.In your own opinion what are some of the challenges you experience when dealing with bereaved mothers?

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19.And what suggestions would you put forth to address them?

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.....

20.From your professional point of view how would you grade the quality of bereavement care offered in KNH to parents after perinatal loss?

Excellent ☐

Good ☐

Poor ☐

Appendix 3b Health workers questionnaire (Kiswahili)

FRAMEWORK FOR BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL

DEMOGRAPHICS

Nambari ya masomo: …… ……

1. Umri: ……. …….
2. Jinsia

☐ Mwanamke

☐ Mwanaume

3. Cadre ya Wafanyakazi:

☐Daktari wa akina mama

☐ Muuguzi

4.Miaka ya uzoefu katika kitengo cha kuhudumia akina mama waja wazito……

5. Umepata mafunzo yoyote katika utunzaji wa wazazi waliopoteza Watoto wao?

☐Ndio

☐Hapana

6. Uzoefu wa upotezaji wa Mtoto wa kibinafsi:

☐Ndio

☐Hapana

7. Dini

☐Kristo

☐Muslim

☐Budhist

☐Lingine: ……. …… ..

8. Je! Umehudumia mama yeyote ambaye amepoteza mtoto kabla ya kujifungua au wakati wa kujifungua katika hiki kitengo?

☐Ndio

☐Hapana

Ikiwa ndio jaza meza hapa chini, hiyo itatuarifu juu ya kufuata kwako kwa mazoea bora ya utunzaji wa wazazi waliopoteza mtoto

	NDIO	HAPANA
1. Sisi kila wakati tunauliza Ultrasound (U / S) kuthibitisha IUFD		
2. Endapo mama amepoteza mtoto sisi huwaita ndugu na jamii yake kuwa kabla ya kuvunja habari mbaya		
3. Tuna chumba tofauti cha ushauri cha kuvunja habari mbaya		
4. Tunao viongozi wa dini za imani tofauti kama hawa akina mama wanawahitaji		
5. Tunawapa dawa ya kumaliza maumivu kwa wale walio na IUFD.		
6. Tunafuatilia ishara muhimu za mama mara kwa mara kama kwa wale walio na ujauzito wa mtoto aliye hai.		

7. Baada ya mama kujifungua: FSB au MSB:		
a) Tunsafisha mtoto		
b) Ninampa mama mtoto		
c) Ninawaruhusu wazazi kumbeba mtoto kwa muda mrefu kama wanavyotaka.		
8. Baada ya mama kumpoteza mtoto mimi huuliza juu ya imani ya kiroho yake na simjazii imani zangu mwenyewe.		
9. Ninawaruhusu kujifungua katika chumba tofauti na wale walio na ujauzito wa mtoto aliye hai		
10. Mimi kila wakati ninahakikisha wanapata dawa ya kukandamiza maziwa.		
11. Tunayo mshauri aliyejumuishwa kwenye idara yetu ambayo huwapo wakati wote wa kuvunja habari mbaya		
12. Mimi humpa mama kila wakati nafasi ya kuuliza maswali juu ya kumpoteza mtoto .		
13. Ninahakikisha kuwa wazazi waliopoteza mtoto wanapata huduma ya baada ya kuzaa na matibabu ya kisaikolojia baada ya kutoka hospitali.		
14.Kwa wale walio na vifo vya watoto wachanga ghafla mimi huwashauri juu ya postmortem.		
15. Ninaathirika kimawazo wakati wa kushughulika wazazi waliopoteza Watoto		
16. Nimepata upotezaji wa mtoto, ikiwa ndio , tueleze kama kushughulikia hawa wazazi waliopoteza watoto kunakupa uvumbuzi?		
17.Baada ya kuwahudumia hawa wazazi tuna daktari wa kisaikolojia wakutuliwaza mawazo.		

18. Kwa maoni yako mwenyewe ni changamoto gani unazopata wakati wa kushughulikia akina mama waliopoteza watoto?

…….
…….……
…….……
……..……..
…….

19. Je! Ni maoni gani unaweza kutoa ili kuboresha huduma kwa wazazi waliopoteza mtoto?

…….
…….……
…….……
……..……
…….
……

Appendix 4a: In-depth Interview Guide

The Affected mother

Framework for bereavement care after perinatal loss: Affected Parents' and health care providers' perspective at Kenyatta National Hospital.
Interviews with women to explore individual lived experiences of bereavement care following perinatal loss.

1. Can you tell me about, your pregnancy, birth and the death of your baby?
- *sex of the baby.*
- *describe what happened, when and how*
- *how was the news broken and by whom, were they alone or with others?*
- *Did you see/ hold your baby after the birth*
    - *Was this your preference?*

2.Can you tell me how you coped when you received the news of your baby's death? *− How did others respond to you following the death of your baby − Experiences with health workers, partner, family, friends?*

3.How are you coping now?
- *What has helped you cope with your baby's death − What could have improved your experience**?***

4.Do you have any particular beliefs which have influenced your experience?
- *Cultural, religious beliefs and traditions.* ***How do you feel about participating in this research?***

How do you feel about participating in this interview?
Is there anything else you might want to add?

5.How do you feel after talking about these experiences, do you want to contact anyone? Family, friend, health worker?

The Affected father

Framework for bereavement care after perinatal loss: Affected parents' and health care providers' perspective at Kenyatta National Hospital

Interviews with partners to explore individual lived experiences of bereavement care following perinatal loss

1.Can you tell me about, partner's pregnancy, birth and the death of your baby?

- *the sex of the baby*
- *Kindly describe what happened, when and how*
- *How the news was broken and by whom, were you with your partner, could you stay with her?*
- *Did you see/ hold your baby after the birth Was this your preference?*

2.Can you tell me how you coped when you received the news of your baby's death? – How did your partner cope?

- ***How did others respond to you following the death of your baby – experiences with health workers, family, friends?***

3.How are you coping now?

- ***How is your partner?***
- ***What has helped you and your partner cope with your baby's death – What could have improved your experience?***

4.Do you have any particular beliefs which have influenced your experience?

- *Cultural, religious beliefs and traditions.*

How do you feel about participating in this research?
How do you feel about participating in this interview? Is there anything else you might want to add?

How do you feel after talking about these experiences, do you want to contact anyone? Family, friend, health worker?

Appendix 4b In-depth interview guide (Kiswahili)

i. Wanawake walioathiriwa

Framework for bereavement care after perinatal loss: Affected parents' and health care providers' perspective at Kenyatta National Hospital.

Mahojiano na wanawake ili kupata uzoefu wa maisha ya mtu binafsi ya utunzaji baada ya kupoteza mtoto.

1. Je! Unaweza kuniambia kuhusu, ujauzito wako, kuzaliwa na kifo cha mtoto wako?
- Jinsia ya mtoto.
- Fafanua yaliyotokea, lini na jinsi
- habari ilivunjwaje na nani, ulikuwa peke yako au na wengine.
- Je! Uliona / kumbeba mtoto wako baada ya kuzaliwa
• Je! Hivyo ndivyo ulivyopendelea?

2. Je! Unaweza kunielezea jinsi ulivyopambana wakati ulipokea habari za kifo cha mtoto wako? - Je! Wengine walikujibu vipi kufuatia kifo cha mtoto wako ; wafanyikazi wa afya, mwenzi, familia, marafiki?

3.Je! Unaendeleaje kwa sasa?
- Ni nini kimekusaidia kukabiliana na kifo cha mtoto wako - Je! Ni nini kingeboresha uzoefu wako?

4. Je! Una imani yoyote ambayo imeathiri uzoefu wako?
- Utamaduni, imani za kidini na mila. Unahisije kuhusu kushiriki katika utafiti huu?
Je! Unajisikiaje kushiriki kwenye mahojiano haya?
Je! Kuna kitu kingine chochote unachoweza kutaka kuongeza?

5.Unasikiaje baada ya kuongea juu ya uzoefu huu, unataka kuwasiliana na mtu yeyote?
Familia, rafiki, mfanyakazi wa afya?

ii. Washirika

Kutathmini kiwango cha utunzaji wa wazazi baada ya kumpoteza mtoto: Mtazamo wa wazazi na ule wa wahudumu wa afya

Mahojiano na washirika wa kutafuta uzoefu wa maisha ya mtu binafsi baada ya kumpoteza mtoto

1. Je! Unaweza kuniambia kuhusu, ujauzito wa mwenzi wako, kuzaliwa na kifo cha mtoto wako?
- Jinsia ya mtoto
- Fafanua kwa fadhili kilichotokea, lini na jinsi kilitendeka
- Jinsi habari ilivunjwa na na nani, ulikuwa na mwenzi wako, uliweza kukaa naye?
- Je! Uliona / kumbeba mtoto wako baada ya mwenzi wako kujifungua? Je! Hilo ndilo lilikuwa pendeleo lako?

2. Je! Unaweza niambia jinsi ulivyopambana wakati ulipokea habari za kifo cha mtoto wako?
- Je! Mwenzi wako alifanikiwa vipi?
- Je! Wengine walikujibu vipi kufuatia kifo cha mtoto wako - uzoefu na wafanyikazi wa afya, familia, marafiki?

3.Je! Unaendeleaje?
- Je! Mwenzi wako yuko vipi?
- Ni nini kimekusaidia wewe na mwenzi wako kukabiliana na kifo cha mtoto wenu
- Ni nini kingeweza kuboresha uzoefu wako?

Appendix 5a: Healthcare Providers Key Informant Interview Guide

Framework for bereavement care after perinatal loss: Affected parents' and health care providers' perspective at Kenyatta National Hospital.

Interviews with healthcare providers to explore individual lived experiences of bereavement care following perinatal loss

1. Tell me about your experiences in providing care to women and families whose baby has died shortly before or during childbirth?

- *describe your role and experiences including personal experiences if appropriate.*

2. Tell me about the preparation you have received for your role in caring for couples whose baby has died?

- *clarify aspects of experiences during education and in practice.*

3.Do you have any particular beliefs which have influenced the care you provide?

- *Cultural or religious beliefs, traditions.*

4.Is there anything you think would help you ensure quality of care for women and families whose baby has died during childbirth?

- *Service organization factors, staffing environment, equipment - Individual factors; education, mentorship/ role modelling*

How do you feel about participating in this research?
How do you feel about participating in this interview?
Is there anything else you would like to add?

Kindly fill in the checklist below that will inform the structure for bereavement care provision in KNH

STRUCTURE OF BEREAVEMENT CARE (CHECKLIST)

If available indicate with a tick if not available use an X

a. Multidisciplinary Team:

- Obstetrician ☐
- Neonatologist ☐
- Primary Nurse ☐
- Grief Counsellor ☐
- Religious Leader ☐

b. Counselling room in labour ward and each of the postnatal ward ☐

c. Bereavement Protocol ☐
d. Training module for healthcare workers on bereavement care ☐
e. Ultrasound for diagnosis of IUFD in Labour Ward ☐
f. Private Labour room for those with IUFD ☐
g. Medication to ensure pain free labour ☐
h. Laboratory test that can be done urgently to investigate cause of the loss ☐
i. Private Postnatal room for those who have had a loss ☐
j. Tools to take momentos:
    - Camera ☐
    - Ink for palm print or foot print ☐
    - Birth card for the baby ☐

Special consideration for those attending postnatal clinic after loss ▱

Appendix 5b: Healthcare providers interview guide (Kiswahili)

Mahojiano ya watoa huduma wa afya kuchunguza uzoefu wao katika kutoa huduma kwa wazazi ambao wamempoteza mtoto wao mchanga muda mfupi kabla au wakati wa kuzaa.

1. Niambie juu ya uzoefu wako katika kutoa huduma kwa wanawake na familia ambazo mtoto mchanga amekufa muda mfupi kabla au wakati wa kuzaa?
- Fafanua jukumu lako na uzoefu pamoja na uzoefu wa kibinafsi ikiwa inafaa.

2. Niambie juu ya maandalizi uliyopokea kwa jukumu lako katika kutunza wazazi ambao mtoto wao amekufa?
- Fafanua vipengele vya uzoefu wakati wa elimu na mazoezi.

3. Je! Una imani yoyote ambayo imeathiri utunzaji unaopeana?
- Imani za kitamaduni au za kidini, mila.

4. Je! Kuna kitu chochote unafikiria kitakusaidia kuhakikisha huduma bora kwa wanawake na familia ambazo mtoto wao amekufa wakati wa kuzaa?
- Sababu za shirika la huduma, mazingira ya wafanyikazi, vifaa au Sababu za kibinafsi; elimu, ushauri / jukumu la kuigwa

Unahisije kuhusu kushiriki katika utafiti huu?
Je! Unajisikiaje kushiriki kwenye mahojiano haya?
Je! Kuna kitu kingine chochote ungependa kuongeza?

Jaza jalada hapa chini ambalo litajulisha muundo wa utoaji wa huduma kwa wazazi waliofiwa katika KNH

UPANGO WA KIWANGO CHA BEREA (CHECKLIST)
a.Ikiwezekana onyesha na cheki ikiwa inapatikana (tumia X)

- Daktari wa wanawake ☐
- Daktari wa watoto ☐
- Muuguzi wa Msingi ☐
- Mshauri wa Huzuni ☐
- Kiongozi wa Dini ☐

b. Chumba cha ushauri nasaha katika wadi ya kazi na kila wodi ya baada ya kuzaa ☐
c. Itifaki ya Kuachana ☐
d. Moduli ya mafunzo kwa wafanyikazi wa huduma ya afya juu ya utunzaji wa wale waliofiwa ☐
e. Ultrasound ya utambuzi katika Kata ya Kazi ☐
f. Chumba cha akina mama cha Kibinafsi kwa wale walio na IUFD ☐
g. Dawa ya kuhakikisha akina mama ambao watoto wameaga kabla ya kujifungua hawana maumivu ☐
h. Mitihani ya maabara ambayo inaweza fanywa haraka kuchunguza sababu ya kupoteza mtoto ☐
i. Chumba cha kibinafsi baada ya kujifungua kwa wale ambao wamepoteza watoto ☐
j. Vyombo vya kuchukua pumu: ☐
 Kamera ☐

 Wino wa kuchapa kwa mitende au kuchapa kwa miguu ☐
Card Kadi ya kuzaliwa kwa mtoto ☐
Ushauri maalum kwa wale wanaohudhuria kliniki ya baada ya kuzaa na kupoteza mtoto☐

Appendix 6a. Focused Group Discussion Guide (English)

For the Affected Parents

Facilitator's welcome, introduction and instructions to participants

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. I realize you are it has been difficult and I appreciate your time.

Introduction: This focus group discussion is designed to assess your experiences on bereavement care. The focus group discussion will take no more than one hour. I will tape the discussion to facilitate its recollection. (switch on the recorder)

Anonymity: Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Ground rules

- The most important rule is that only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished.
- There are no right or wrong answers
- You do not have to speak in any particular order
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you
- You do not have to agree with the views of other people in the group Does anyone have any questions? (answers).
- OK, let's begin **Warm up**
- First, I'd like everyone to introduce themselves. Can you tell us your name?

Introductory question

I am just going to give you a couple of minutes to think about your experience after child loss while being attended to in KNH. Is anyone happy start us off?

Guiding Questions

1. How did you find out that you lost the baby?
2. What things did the healthcare providers do that were helpful?
3. What things did the healthcare providers do that were not helpful?
4. How did other family members and the community you live in help you deal with the loss?
5. How has child loss affected your relations as a person in: your marriage, society and place of work?
6. What can of assistance of services would you recommend for couples in a similar situation in this health facility to assist them cope with their loss?

Concluding Question

Is there anything extra /important you would like to share with us about your experience?

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting and you were able to open up your feelings

- If there is anything you are unhappy with or wish to complain about, please contact the local PI or speak to me later
- I would like to remind you that any comments featuring in this report will be anonymous

Appendix 6b Focus Group Discussion Guide (Kiswahili)

Kwa Wazazi Walioathirika

Kukaribisha, utangulizi na maagizo kwa washiriki

Karibu na asante kwa kujitolea kushiriki katika kundi hili la umakini. Umeulizwa kushiriki kwani maoni yako ni muhimu. Ninatambua ni wewe imekuwa ngumu na ninathamini wakati wako.

Utangulizi: Majadiliano ya kikundi hiki cha kuzingatia yameundwa kutathmini uzoefu wako juu ya utunzaji wa kufiwa. Majadiliano ya kikundi cha kuzingatia hayatachukua zaidi ya saa moja. Nitatilia mkazo mazungumzo ili kuwezesha kumbukumbu yake. (Washa kinasa)

Kutokujulikana: Licha ya kuchapishwa, ningependa kukuhakikishia mazungumzo hayo hayatajulikana. Bomba hilo litahifadhiwa kwa usalama katika kituo kilichofungwa hadi zitaandikwa neno kwa neno, basi litaharibiwa. Maelezo yaliyoandikwa ya kikundi cha kulenga hayatakuwa na habari ambayo inaruhusu masomo ya mtu binafsi kuunganishwa na taarifa maalum. Unapaswa kujaribu kujibu na kutoa maoni kwa usahihi na ukweli iwezekanavyo. Mimi na washiriki wengine wa kikundi cha kulenga tungethamini ikiwa ungekataa kujadili maoni ya washiriki wengine wa kikundi kiliyokuzingatia. Ikiwa kuna maswali au majadiliano yoyote ambayo hutaki kujibu au kushiriki, sio lazima ufanye hivyo; Walakini tafadhali jaribu kujibu na kuhusika iwezekanavyo.

Sheria

• Utawala muhimu zaidi ni kwamba mtu mmoja tu huongea kwa wakati mmoja. Kunaweza kuwa na jaribu la kuruka wakati mtu anaongea lakini tafadhali subiri hadi wamalize.
• Hakuna majibu sahihi au sahihi
Sio lazima kusema kwa mpangilio wowote
• Unapokuwa na kitu cha kusema, tafadhali fanya hivyo. Kuna wengi wako kwenye kundi na ni muhimu kwamba nipate maoni ya kila mmoja wako
• Sio lazima ukubaliane na maoni ya watu wengine kwenye kikundi • Je! Kuna mtu yeyote ana maswali? (majibu).
• Sawa, wacha tuanze Joto
• Kwanza, napenda kila mtu ajitambulishe. Je! Unaweza kutuambia jina lako?

Swali la utangulizi

Nitakupa dakika chache za kufikiria juu ya uzoefu wako baada ya kupotea kwa mtoto wakati unahudhuriwa katika KNH. Je! Kuna mtu yeyote mwenye furaha anatuanzisha?

Maswali ya kuongoza utafiti

1. Je! Umegunduaje kuwa umepoteza mtoto?
2. Ni vitu gani ambavyo watoa huduma ya afya walifanya ambayo ilikuwa ya msaada?
3. Ni mambo gani ambayo watoa huduma ya afya walifanya ambayo hayakuwa msaada?
4. Je! Wanafamilia wengine na jamii unayoishi ili kukusaidia vipi kukabiliana na upotezaji?
5. Kupotea kwa mtoto kumeathiri vipi mahusiano yako kama mtu katika: ndoa yako, jamii na mahali pa kazi?
6. Je! Ni nini cha msaada wa huduma ambacho unaweza kupendekeza kwa wenzi walio katika hali kama hii katika kituo hiki cha afya kuwasaidia kukabiliana na upotezaji wao?

Tamatisho la Maswali
Je! Kuna kitu cha ziada / muhimu ungependa kushiriki na sisi juu ya uzoefu wako?

Tamatisho

Asante kwa kushiriki. Hii imekuwa majadiliano yenye mafanikio sana
Maoni yako yatakuwa mali ya muhimu katika somo
- Tunatumahi kuwa umepata mjadala huo wa kupendeza na umeweza kufungua hisia zako
- Ikiwa kuna jambo ambalo hufurahii au unalalamika kulalamika juu yako, tafadhali wasiliana na PI wa karibu au nizungumze baadaye
- Napenda kukukumbusha kwamba maoni yoyote yaliyo katika ripoti hii hayatakuwa ya jina

Appendix 7. ERC approval certificate

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
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Telegrams: varsity
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KENYATTA NATIONAL HOSPITAL APPROVED 30 JAN 2020 KNH/UoN-ERC

Ref: KNH-ERC/A/50

30th January 2020

Dr. Lydia Wanja Njiru
Reg. No.H58/7141/2017
Dept.of Obstetrics and Gynaecology
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Njiru,

RESEARCH PROPOSAL - STANDARDS OF BEREAVEMENT CARE AFTER PERINATAL LOSS: AFFECTED PARENTS' PERSPECTIVE AND HEALTH CARE PROVIDERS' PERSPECTIVE AT KENYATTA NATIONAL HOSPITAL (P703/08/2019)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above research proposal. The approval period is 30th January 2020 – 29th January 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
f. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website http://www.erc.uonbi.ac.ke

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UoN
The Chair, Dept. of Obstetrics and Gynaecology, UON
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