Knowledge, Attitude and Practice of Bereaved Parents and Health Care Providers towards Autopsies in Children under Five years at Kenyatta National Hospital

A Dissertation submitted in Partial Fulfillment of the Degree of Masters of Medicine (Paediatrics and Child Health), University of Nairobi.

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DECLERATION

This dissertation is my original work and has not been presented for the award of a degree in any other university.

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ACKNOWLEDGEMENTS

I wish to express my sincere appreciation to:

- My supervisors Prof. Rachel Musoke, Dr. Ahmed Laving and Dr. Emily Rogena for their guidance, support, patience and constructive criticism throughout the study.
- All the parents and health care providers for their patience and willingness to participate in the study.
- My family for their unrelenting support and encouragement.
- My fiancé Dr. Mark Michael Siboe for his support and understanding during the whole study period

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LIST OF ABBREVIATIONS

AIDS – Acquired Immunodeficiency Syndrome

HCP – Health care providers

HIV – Human Immunodeficiency Virus

IMR – Infant Mortality Rate

KDHS – Kenya Demographic Health Survey

KNH – Kenyatta National Hospital

KHERC - Kenyatta Hospital Ethics Research Committee

MDG – Millennium Development Goal

NBU – Newborn Unit

NNS – Neonatal Sepsis

PICU – Paediatric Intensive Care Unit

USA – United States of America

UK – United Kingdom

U5MR – Under 5 Mortality Rate

DEFINITION OF TERMS

Autopsy: examination of bodies after death to determine the cause of death or the extent of disease

Bereavement: period of mourning and grief following the death of a loved person

Mourning: word used to describe public rituals or symbols of bereavement

Health care providers: For the purpose of this study, refers to nurses, interns (medical and clinical) paediatric residents and paediatricians working in the study areas during the study period

Under-five mortality: the probability of dying between birth and the fifth birthday

ABSTRACT

Introduction:

Knowledge, attitudes, and practices of health care professionals and the public toward autopsy are important as they will give information regarding factors that contribute to the low rate of autopsies in children under 5 years.

Objectives:

To evaluate the knowledge, attitude and practice of bereaved parents and health care providers towards autopsies in children under 5 years and assess the relationship between parents' practice and socio demographic characteristics.

Methods:

This was a cross-sectional descriptive survey. Respondents included parents whose children had died aged 0-60 months and health care providers working in Kenyatta National Hospital paediatric wards and newborn unit. Ward mortality records were used to identify potential study participants as well as obtain child's biodata and clinical cause of death. The parents were then approached within 24 - 48 hrs of the child's death, asked to participate in the study, allowing them to provide voluntary informed consent. Participants for the focused group discussion were identified randomly and their contact information obtained from ward records. The parents were contacted and asked to voluntarily participate in the discussion. Written informed consent as well as consent to tape record the discussions was obtained. Health care providers were identified and asked to participate in the study. Those who agreed signed written consent and then filled in a questionnaire.

Results:

The study enrolled 95 bereaved parents and 95 health care providers. Among the 95 deceased children, 67.4 % did not have an autopsy request.

Knowledge on autopsy was high among the bereaved parents (79%) and a positive attitude towards autopsy was found in 55.7%, which was significantly associated with respondent's level

of education. Among the 31 parents asked to consent to an autopsy, 29% consented and 71% declined. The main reason for consenting was to confirm cause of death while those who declined, the main reasons were that religion forbade autopsy and a feeling that diagnosis should have been made before the child's death.

Majority (69.5%) of health care providers showed a positive attitude towards autopsy. Consultants and paeadiatric residents had a more positive attitude compared to interns ($p< 0.001$) and nurses ($p=0.011$). Clinical experience of >15 years was associated with a more positive attitude. The main barriers to obtaining consent were lack of formal training in obtaining consent and failure of autopsy results to be availed in a timely manner.

Conclusions:

Bereaved parents had adequate knowledge of autopsies with a positive attitude being significantly associated with the level of education. Majority of parents were not asked to consent to an autopsy on their deceased child. Of those asked many declined mainly due to religious beliefs. Health care providers had a positive attitude to autopsy which was significantly associated with their cadre and years of experience. The main reasons given for not obtaining consent for autopsy were lack of formal training in obtaining consent and failure to obtain autopsy results in timely manner.

Recommendations:

Bereaved parents need to be counseled on the need for autopsy on their deceased child and potential barriers to consent. Health care providers should be trained on counseling of parents after death of their child and on how to request an autopsy. Further qualitative and quantitative research, with a larger number of participants, should be performed.

1. INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction and Epidemiology

The term autopsy refers to the systemic examination of a dead body for medical, legal and scientific purposes (1). Presently the autopsy is the accepted gold standard for determination of cause of death. The term autopsy means "see for yourself" and is used interchangeably with the word necropsy (1).

Autopsy is a form of post-mortem examination procedure, post-mortem being a Latin word while autopsy is a Greek word.
A postmortem examination can be carried out through either:-

1. Limited dissection – in circumstances where an infectious disease is suspected, a certain region or organ of the body is targeted (for example, the lungs) so as to limit spillage of fluids or body material.
2. Complete dissection i.e. an autopsy.
3. View and grant – an external examination of the dead body.

There are two types of autopsies/postmortem examinations (1):

1. Hospital/Clinical autopsy – made at the behest of the medical personnel or relatives of the deceased.
2. Medico legal/Forensic autopsy – these are mandated by law.

Autopsy examination provides a good index of the quality of patient care, both in terms of the accuracy of clinical diagnosis and the quality of treatment given(2).
An autopsy is important in (3, 4):

- establishing the cause of death
- assisting in determining the manner of death
- comparing the ante mortem and postmortem findings
- producing vital statistics, or monitoring public health

The findings at autopsy can be classified into 5 classes, that is, according to Goldman et al (3). This classification is based on the concordance or discordance of ante mortem and post mortem diagnosis and the impact the new diagnosis found at autopsy would have had, had it been detected before death of the individual (Appendix 2,table 1).

An autopsy is also a powerful tool in assisting families in coping with the grieving process and in counseling them regarding future pregnancies (5). Autopsies also generate accurate vital statistics, provide pathological descriptions of new diseases, and offer powerful tools for education and quality assurance (5).

Despite the crucial role that autopsy plays in the development of the science and practice of medicine, autopsy rates have been declining throughout the world in recent decades (6). The reasons advanced for this decline are varied and complex. Medical reasons for the decline include advances in diagnostic techniques that often mean that clinicians have substantial information about patients before their demise, failure to obtain consent from patient or relatives, fear of litigation, a shortage of pathologists, and concern about costs (7, 8).

Despite these reasons, knowledge, attitudes, and practices of health care professionals and the public toward autopsy have not been well studied. There are few studies on attitude towards autopsy from Africa where clinical autopsy rates have also been on the decline (2).

Epidemiology

Under-5 mortality rate is a leading indicator of the level of child health and overall development in countries. It is also a MDG indicator. Almost 90% of all child deaths are attributable to six conditions: neonatal causes, pneumonia, diarrhea, malaria, measles, and HIV/AIDS (9). Literature has shown that new diagnosis is found at autopsy in 29% – 79% of cases of autopsies done on children 0-60 months of age (10-12).

Infant and child mortality rates are regarded as indices that reflect the degree of poverty and deprivation of a population. Under-five mortality and infant mortality rates are two of the indicators used to monitor child health under MDG 4 (13) (Appendix 2, table 2).

For the five years immediately preceding KDHS 2008-2009 (approximate calendar years 2004-2008), the infant mortality rate was 52 per 1,000 live births and the under-five mortality was 74 deaths per 1,000 live births. This implies that one in every 19 children born in Kenya dies before his or her first birthday, while one in every 14 does not survive to age five. Neonatal mortality was 31 deaths per 1,000 live births, while post neonatal mortality was 21 per 1,000 live births during the same period. Thus, 60% of infant deaths in Kenya occur during the first month of life (13).

The target of MDG 4 is to "Reduce by two thirds, from 1990 to 2015, the under-five mortality rate". Efforts to improve child survival can be effective only if they are based on reasonably accurate information about the causes of childhood deaths (13).

Gohill et al (14) in 1979 reviewed autopsies done at the University teaching Hospital in Zambia and found that the autopsy rate was 17% for all deaths and 10% for neonatal deaths.

In 2010, 2315 children died at the KNH (15). Of the 485 autopsies done in the same year only 6% were on children (0-18yrs) with neonates making up 1.2% of the total (16).

1.2 Literature Review

1.2.1 Findings at autopsy in children

Kumar et al (17) looked at trends in paediatric autopsy rates during the period 1984 – 1993 and the concordance between ante mortem and postmortem diagnoses. They found that autopsies were performed in 26% of infants 12 months or younger, 60% of children between 13 and 60 months of age, and 100% of children 61 months or older. In 34% of cases, new diagnoses were made at autopsy, including 7 cases where new findings, if known before death, would likely have resulted in a change in treatment or improved survival.

A study by Stambouly et al (18) examined the correlation between clinical diagnoses and autopsy findings in children who died in the paediatric intensive care unit (PICU). Of the 193 patients who died during the 7 and a half year study period, 50 (26%) had autopsies performed. The mean age was 34.7 months. In 10% of the cases autopsy revealed a major finding which would have altered clinical management and might have resulted in cure or prolonged survival had it been detected prior to death.

Narayana et al (19) looked at autopsy findings in children admitted to the PICU. Autopsies were performed in 31 cases (26% of deaths). Major discrepancies between clinical diagnoses and autopsy findings (Goldman classes I or II) were found in 8 (25% of autopsies), minor discrepancies (Goldman class III or IV) in one case.

The results of autopsies done on neonates have likewise shown similar findings. Kumar et al (10) found that of 296 autopsies done over a 10 year period, new diagnoses were made at autopsy in 44% of cases. Major discordances were identified in 35 infants (12%); minor discordances in 95 (32%). Autopsies were more likely to reveal new diagnoses in infants born at 28 to 36 weeks' gestation and in those whose mothers had no prenatal care.

In a retrospective review of patients records over a 10 year period (1990-1999), Brodle et al (11) found that of 209 autopsies done, new information was obtained in 50 (26%) autopsies. In 6 (3%) of the cases this information was crucial for future genetic counseling. The only significant factor associated with consent for autopsy was increased gestational age, with more parents consenting to autopsy as gestational age increased. Elder et al (12) looked at autopsy findings in preterm neonates and found that in 79% of the cases a new diagnosis was detected at autopsy. The autopsy findings led to a significant change in the clinical diagnoses in 28% of the cases.

1.2.2 Knowledge, attitude and practice towards autopsies

Van Mater et al (20) found that previous perinatal loss or abortion, extreme prematurity, and very low birth weight of the infants were important differentiating factors between parents who gave and those who refused consent for neonatal autopsy. The infant's age at death and duration of time spent in the NICU where the infant died were also important with a trend toward increased consent in older infants and those hospitalized for longer periods. They also looked at Physicians' attitudes regarding importance of neonatal autopsy and found that the overall importance increased with advancement in staff position and experience in requesting for consent.

A study by Stolman et al (21) looked at the attitude of paediatricians and paediatric residents in obtaining permission for autopsy and found that although 98% agreed that the autopsy provides valuable information, several factors influenced the failure to obtain consent for an autopsy i:e

- physician belief that the family felt the body would be desecrated 37%
- physician belief that the family would be upset 35%
- physician belief that little information would be obtained 18%
- 17% did not ask permission for autopsy if the family is upset.

In the UK, Snowdon et al (22) found that neonatologists expressed discomfort over approaching bereaved parents and that autopsies were unnecessary if the cause of death seemed apparent/premature baby.

Hooper et al (23) sought to investigate the nature of physician attitudes about autopsy and to relate these attitudes to certain physician demographic variables. They found that 77% agreed that autopsy results could affect their medical practice, and 73% disagreed that the accuracy of modern diagnostic procedures make autopsy unnecessary. Interestingly, 72% did not believe that litigation concerns play a role in the decision to request autopsy. One of the most crucial factors influencing attitudes is the physician's level of experience with autopsy in training and practice. Among other interesting results was that strength of belief in autopsy relevancy correlates significantly with greater prior exposure to the autopsy. In a sense, the current low autopsy rates

may be self-perpetuating because of the paucity of and decreasing experience with autopsy by succeeding generations of clinicians.

McHaffie et al (24) in Scotland sought to determine parents' views on autopsy after treatment withdrawal. All except one couple were asked for permission for postmortem examination; 38% refused. The main reasons for consenting were to obtain answers to their questions, to help others and to obtain information that may influence future pregnancies. The main reasons for declining were concerns about disfigurement, a wish to have the child left in peace, and a feeling that an autopsy was unnecessary because the parents had no unanswered questions. The diagnosis, the age of the child, and the approach of the consultant appeared to influence consent rates.

In Africa there is paucity of literature on the knowledge, attitude and practice towards autopsies. Two studies, one in Zambia, the other in Nigeria have been done to explore this issue.

In Zambia, Lishimpi et al (2) identified the main reasons for parents' refusal to consent for necropsy. Of the parents interviewed, 43% felt that the diagnosis should have been made when the child was alive, 26.5% refused because a death certificate had already been issued and in 8.6%, ancestral spirits forbade the mutilation of dead bodies.

Oluwasola et al (6) in Nigeria looked at the knowledge, attitude, and perceptions of doctors and relatives of deceased patients towards autopsies. Less than half (42%) of relatives demonstrated satisfactory knowledge of autopsy and 32% indicated they would consent to autopsy on themselves. Most (94.6%) of those who were able to explain autopsy had 7 to 12 years of education. Most (82%) of the relatives that expressed unwillingness to consent to autopsy were Muslims. Christians were found to be about 6 times more likely to consent to autopsy on themselves than Muslims.

Fear of mutilation of body ranked as the highest reason for autopsy refusal. Others were concerns about delaying the funeral, objection expressed by the patient before death, and deceased considered too young or too old. Majority (95%) of the doctors approved the practice of autopsy and 93.8% agreed that there is need to improve public awareness on the benefit of

autopsy. They found that the most common reason that doctors think is responsible for refusal of patients' relatives to give consent for autopsy was fear of mutilation of the body of their deceased. Others were religious reasons, concerns about delays in funeral, concern about removal of organs or body parts, lack of justification of autopsy, and lack of appreciation of the benefit of the procedure to the deceased patient.

2. STUDY JUSTIFICATION

Literature has shown that in developed countries, despite advancement in diagnostic facilities, discrepancies are present between the ante mortem and post mortem diagnosis, and autopsy rates have been on the decline for the past decade. In Kenya due to the limited diagnostic facilities available, accuracy of diagnosis is a challenge. This can be overcome by performing autopsies so as to determine the actual causes of death and thus develop proper diagnostic algorithms.

In Kenya no studies have been done to ascertain the reasons for the low rates of autopsies in children. Clinicians and parents' level of knowledge about and attitudes toward the autopsy are critical factors in determining whether an autopsy will be requested and if permission will be obtained.

Once determined cause-of-death information can lead to prioritization of interventions and planning for their delivery, determine the effectiveness of disease-specific interventions, and assess trends in disease burden in relation to national and international goals.

The knowledge obtained shall lead to improved care and hopefully reduction in mortality rates.

3. STUDY UTILITY

The findings from this study give information regarding factors that contribute to the low rate of autopsies in children under 5 years.

The findings of this research provide an understanding of the association between parents and health care providers' knowledge, attitudes, practices and beliefs; and the low rate of autopsies in children under 5 years.

4. OBJECTIVES

4.1 PRIMARY OBJECTIVES

1. To explore knowledge, attitude and practice of bereaved parents towards autopsies in children under 5 years of age.

2. To determine the attitude and practice of health care providers towards autopsies in children under 5 years of age.

4.2 SECONDARY OBJECTIVE

1. To ascertain the relationship between parents' practice as regards autopsies and their sociodemographic characteristics i.e.: age, ethnicity, level of education and religion.

5. METHODOLOGY

5.1 Study Design

This was a cross-sectional descriptive study utilizing qualitative and quantitative methods of data collection.

5.2 Study Population

The study population included parents of children who had died aged 0-60 months and health care providers working at the KNH paediatric wards and newborn unit.

5.3 Study Area

The study was carried out at the Kenyatta National Hospital, located in Nairobi, which is the country's main National Referral and Teaching Hospital. It also serves the population of Nairobi and its environs as a Provincial Hospital. The study was carried out in the Newborn unit & Paediatric wards of the Hospital.

5.4 Study Period

The study was carried out in the year 2011 (July – December).

5.5 Inclusion Criteria

- Parents of children 0-60 months who had died at the KNH during the study period.
- Parents enrolled had written informed consent.
- Nurses, interns (medical officers and clinical officers), paediatric residents and paediatricians at the KNH newborn unit & paediatric wards who had cared for children 0-60 months.

5.6 Exclusion Criteria

- Parents who declined to give consent.
- Nurses, interns (medical officers and clinical officers), paediatric residents and paediatricians who declined to give consent

5.7 Sample size Determination

5.7.1 Bereaved Parents

The sample size was calculated using Fisher's Formula (25)

$$n = \frac{Z^2 P (1-P)}{d^2}$$

Where:

- n = minimum sample size
- Z = Z statistic for a 95% level of confidence = 1.96
- P = expected proportion = 42% as per Oluwasola et al (6)
- d = precision = 0.10

Thus n = 93

5.7.2 Health care Providers

The sample size was calculated using Fisher's Formula (25)

$$n = \frac{Z^2 P (1-P)}{d^2}$$

Where:

- n = minimum sample size
- Z = Z statistic for a 95% level of confidence = 1.96
- P = expected proportion = 95% as per Oluwasola et al (6)
- d = precision = 0.045

Thus n = 90

The approximate number of HCP's is as follows

- Nurses (Newborn Unit & Paediatric wards) – 150
- Interns - 50
- Paediatric Residents – 60
- Paediatric Consultants (including Neonatologists) – 30

Thus a proportion of 5 was used to ascertain the minimum number of each type of HCP needed:

- Nurses – 46
- Interns- 16
- Paediatric Residents – 18
- Consultants – 10

5.8 Study Procedures

5.8.1 Bereaved Parents

5.8.1.1 Recruitment Procedure

Potential study participants were identified from the wards mortality records.
The investigator or research assistants then approached the specific parents within 24 - 48 hrs of the child's death, and explained the purpose and methods of the study allowing the parent to provide voluntary informed consent.
For parents who had already consented to an autopsy on their child, the principal investigator then facilitated performance of the autopsy by the Pathologist.

5.8.1.2 Data Collection

Following selection of study subjects, the child's biodata and clinical cause of death were collected from the deceased child's record. Data was then be collected from the identified bereaved parents 24 – 48 hrs after the child's death by administration of a pretested questionnaire to both or one of the parents, by the principal investigator or research assistants.
This was done mainly during the day (9am to 5pm) as it was difficult to get parents who came before or after that time.
A Focus group discussion was conducted with bereaved parents in the last month of the study period by the principal investigator.

5.8.1.2.1 Key Informant Interviews

The questionnaire administered to the bereaved parents enrolled in the study sought to establish the following details:

- Whether an autopsy was requested or not
- Parents age, ethnicity, level of education and religion
- Parents understanding of the term autopsy
- Parents attitude towards autopsy: A positive attitude was indicated if one agreed to all 3 of the following statements/questions regarding autopsy:-
    - There is need to improve public awareness on autopsies
    - I approve of the practice of autopsy
    - Should a reason arise, would you consent to an autopsy procedure being performed on you?
- Parents practice as regards autopsy for their recently deceased child

5.8.1.2.2 Focus Group Discussion

The principal investigator conducted a focus group discussion with bereaved parents on whom the questionnaire had not been administered, that is, parents who were bereaved after the desired sample size had been obtained. Their contact information (mobile telephone number) was obtained from the ward records. The parents were contacted and asked to voluntarily participate in a focus group discussion with the aim of having 8-12 participants in the group.

Written informed consent was obtained from participants as well as consent to tape record the discussions. A preamble stating the current problem of low autopsy rate in children was explained to the participants. The discussions then followed a prepared autopsy topic guide to assess the parents' attitudes with regards to autopsies in children.

5.8.2 Health care Providers

Health care providers working in the newborn unit and paediatric wards were identified and asked to participate in the study. Those who agreed signed written consent and were then given a questionnaire which they filled.

The self administered questionnaire sought to establish the following details:

- HCPs experience as regards autopsy
- Attitude towards autopsy (measured using the Likert scale).
  A positive attitude was indicated if one agreed or strongly agreed that autopsies are capable of providing relevant findings that could change future clinical practice, as well disagreed or strongly disagreed that current diagnostic procedures are so accurate that there is little need for autopsies.

5.9 Data management and analysis

Data management and analysis was conducted using two approaches depending on the type of data (quantitative or qualitative). At the end of the analysis methodological triangulation of data collected by quantitative and qualitative techniques was undertaken to obtain consensus.

The following section describes in detail the methods used in handling and analyzing data from different sources.

5.9.1 Quantitative data

Questionnaires were used to collect data on the bereaved parents' knowledge, attitude and practice, as well as health care providers' attitude and practice regarding autopsy. These data were entered into a database designed in MS Access. During the design of the database, range checks and entry options (implemented using drop downs and tick boxes) were included so as to reduce errors during data entry. The data was then verified and cleaned. Any inconsistencies noted during data cleaning were corrected by referring back to the original questionnaires. Data was then transferred to SPSS (version 17) for analysis.

Data analysis was conducted using SPSS version 17.0 software. Univariate description of each variable in the dataset was conducted using SPSS procedures for calculating means (SD) and medians (ranges) for continuous variables and frequency tables and graphs for categorical variables.

The main study outcomes were estimated as the percentage of parents (of those asked to consent) agreeing to an autopsy on their deceased child (practice), the percentage with adequate knowledge regarding autopsy and percentage displaying positive attitude. As well as, percentage of health care providers who had counseled parents on autopsy and percentage of those with positive attitude towards autopsy. Chi square test were used to investigate whether parents' practice differed according to their socio-demographic characteristics.

5.9.2 Qualitative data

Data collected during the focus group discussion using interview guides was transcribed and cleaned by the researcher following translation of any responses not provided in English. These data were manually coded into themes emerging from the discussions to help understand the parents' experience.

6.0 STUDY RESULTS

A total of 190 respondents were enrolled in the study, 95 bereaved parents and 95 health care providers.

6.1 Bereaved Parent's knowledge, attitude and practice

6.1.1 Demographics of Bereaved parents (Table 1)

The ratio of mothers-to-fathers in the study was approximately 1:1 with fathers constituting 53.7% of the participants and mothers accounting for the remaining 46.3%. The modal age group for parents in the study was 31 to 40 years with an average age of 31.8 years (SD ± 2.1 years). Approximately one-half (49.5%, n = 47) of the parents were found within this age group.

Table 1: Demographic characteristics of bereaved parents

	Frequency	**%**
Relationship with deceased child		
Mother	44	46.3
Father	51	53.7
Age of parent in years		
<20	2	2.1
21-30	39	41.1
31-40	47	49.5
41-50	7	7.4
Tribe or ethnicity		
Kikuyu	38	40.0
Luo	16	16.8
Luhya	15	15.8
Kamba	14	14.7
Kalenjin	6	6.3
Not stated	6	6.3
Formal education		
Primary	20	21.1
Secondary	49	51.6
Tertiary	26	27.4
Religion		
Catholic	22	23.2
Protestant	71	74.7
Not stated	2	2.1
Total	**95**	**100**

As shown in Table 1 above, all the parents reported having attended formal education. Most (50.6%) had attained secondary level education, and almost similar proportions indicated that they had attended primary (21.1%) or tertiary (27.4%) level education. Approximately three-quarter (74.7%) of the respondents were protestants and 23.2% professed Catholicism.

With regard to ethnicity, 38 (40%) parents reported that they belonged to the Kikuyu ethnic group. The other common ethnic groups were Luo (16.8%), Luhya (15.8%), and Kamba (14.7%).

6.1.2 Deceased child's biodata

There were 47 (49.5%) male and 48 (50.5%) female children who had died during hospitalization giving a male-to-female ratio of 1:1.

The length of hospital stay prior to death for this group of children ranged from a few hours to more than 14 days (Average 4.2 days). Most of the deaths (57.9%, n = 55) occurred among children who had stayed in hospital for periods ranging from 1 to 7 days. Approximately 10% of the deaths occurred after 14 days of hospital stay and 14.7% of deaths occurred within the first day of hospitalization. These findings are summarized in table 2 below.

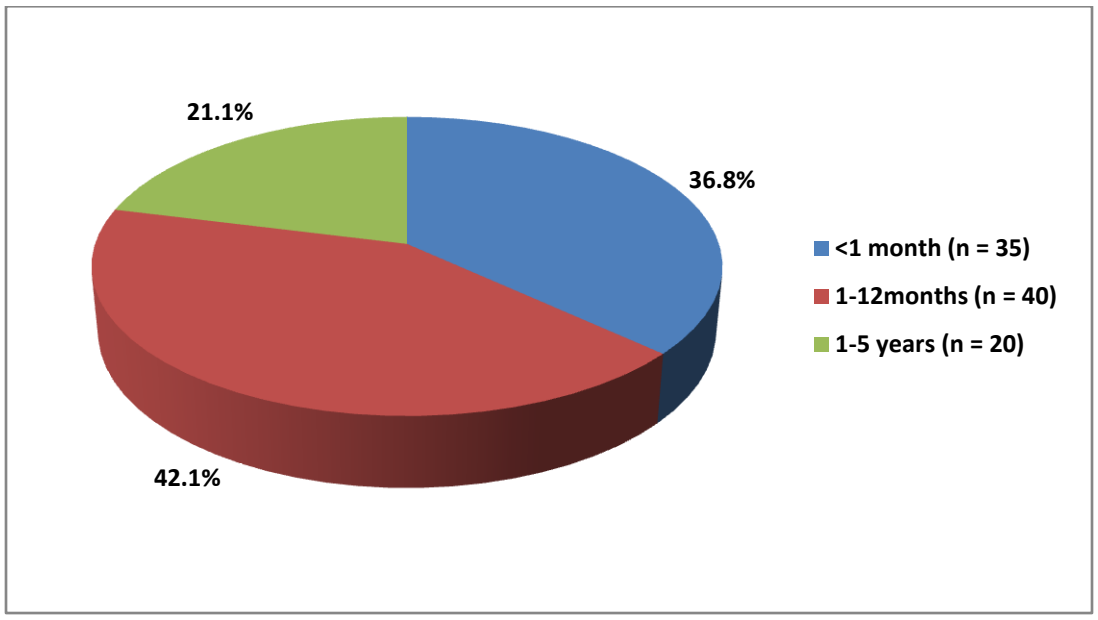
Table 2: Sex and length of hospital stay of deceased children

	Frequency	**%**
Child's sex		
Male	47	49.5
Female	48	50.5
Length of stay (days)		
<1	14	14.7
2-7	55	57.9
8-14	17	17.9
>14	9	9.5
Total	**95**	**100**

6.1.2.1 Child's age at death

Figure 1 shows age distribution of the deceased children whose parents participated in the study. Infants (1 to 12 months) accounted for 42.1% (n = 40) of the deaths and were followed by neonates (< 1 month) who accounted for 36.8% (n = 35) of the deaths. The remaining 20 (21.1%) children were aged between 1 and 5 years of age. The average age was 10.4 months (SD ± 2.8 months).

Figure 1: Age of deceased children at time of death



6.1.2.2 Clinical diagnosis at time of death

Neonatal sepsis was the single most common cause of hospitalization prior to death in this sample accounting for 18 (19%) of the admissions. Overall, a diagnosis of pneumonia, occurring either alone (16.8%, n = 16) or in combination with one of diarrhea (9.5%), or malaria (3.2%) was the most common diagnosis. Other common single diagnoses were meningitis/meningo encephalitis (14.7%, n = 14), HIV/ AIDS (10.5%, n = 10) and prematurity (9.5%, n = 9).

Eleven children suffered from other disorders including lymphoproliferative disorders, tuberculosis, hepatitis, bleeding disorder, intracerebral hemorrhage, diabetic ketoacidosis, severe anemia, and sickle cell crisis.

These findings are summarized in table 3 below.

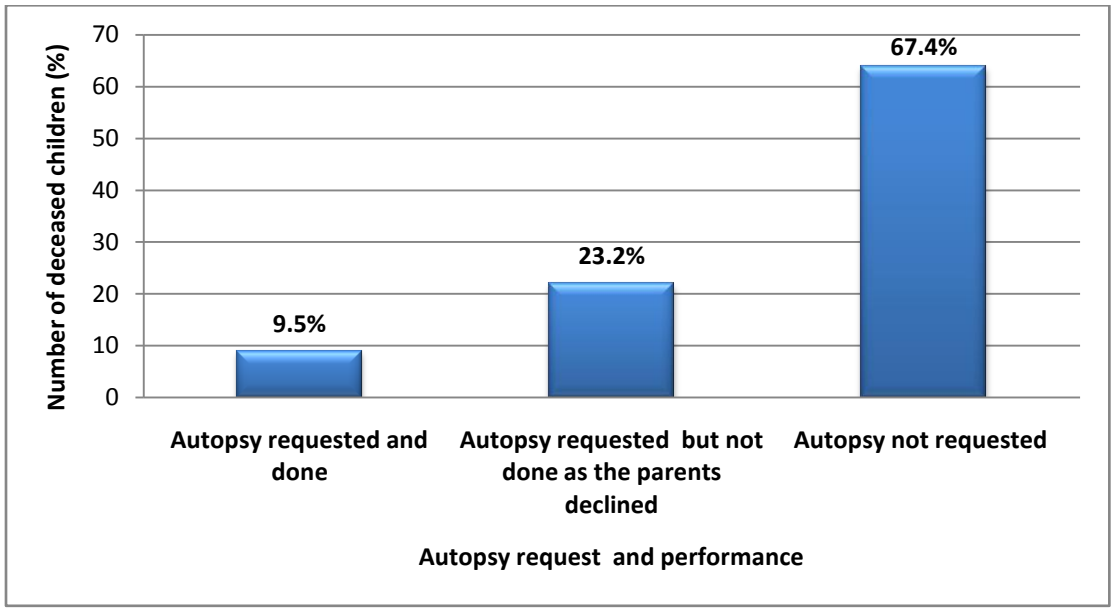
Table 3: Primary clinical diagnosis of the deceased children at time of death

Primary Diagnosis	Frequency	%
Neonatal sepsis	18	19
Pneumonia	16	16.8
Meningitis/ meningoencephalitis	14	14.7
HIV/ AIDS	10	10.5
Prematurity	9	9.5
Pneumonia & Diarrhea/Malaria	9	9.5
NNS & asphyxia	3	3.2
Diarrhea and Dehydration	2	2.1
NNS & Diarrhea	2	2.1
Malaria	1	1.1
Others	11	11.6
Total	**95**	**100**

6.1.2.3 Autopsy request among the deceased children (Figure 2)

Approximately two-thirds (67.4%, n = 64) of the children did not have an autopsy request. Among the remaining 31 children who had an autopsy request, 9 (9.5%) actually had an autopsy conducted while 22 (23.2%) had an autopsy requested but an autopsy was not conducted as the parents declined.

Figure 2: Autopsy practice related to the 95 deceased children



6.1.3 Parental knowledge of autopsy

Among the 95 parents recruited in this study, 20 (21%) reported that they did not know what an autopsy was. Seventy five (79%) parents indicated that an autopsy was performed to determine the cause of death. All the responses on parents' knowledge on autopsy are presented in Table 4 below.

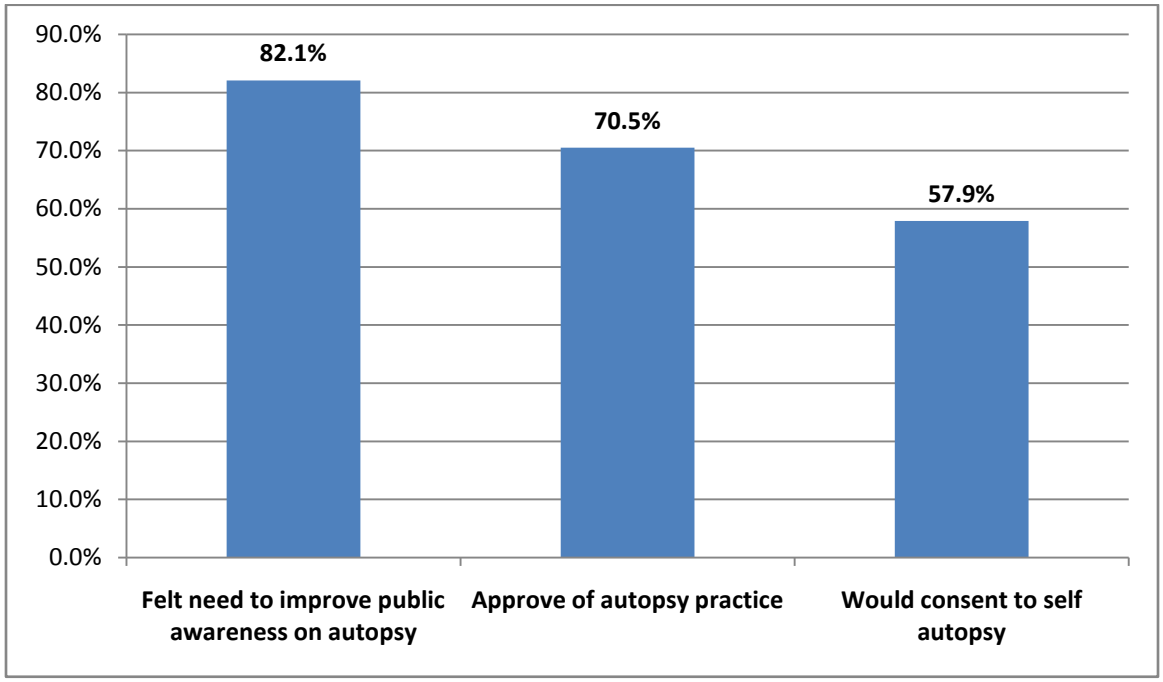
Table 4: Knowledge of autopsy among parents of deceased children at KNH

	Yes, n (%)	**No, n (%)**
Autopsy is wholly an academic exercise	2 (2.1)	93 (97.9)
Autopsy involves examination of all the internal and external organs of a corpse	3 (3.2)	92 (96.8)
Autopsy is performed to determine cause of death	75 (79)	20 (21)
Autopsy enables monitoring of competence of medical staff	1 (1)	94 (99)
Autopsy can provide emotional assurance for relatives of deceased	8 (8.4)	87 (91.6)

6.1.4 Parents attitude regarding autopsies

Of the parents recruited, 55.7% had a positive attitude towards autopsy compared to 44.3% who had a negative attitude. Figure 3 below shows the percentage of bereaved parents who agreed to the three attitude statements/questions. Seventy eight (82.1%) reported that they felt a need to improve public awareness on autopsy, 67 (70.5%) approved the practice of autopsy if a need arose and 55 (57.9%) reported that they would consent to a self autopsy. Overall, a total of 53 (55.7%) respondents gave a positive response to all the three attitude statements displaying a positive attitude towards autopsy.

Figure 3: Bereaved parents who agreed with attitude statements



6.1.4.1 Positive attitude and patient characteristics

Positive attitudes towards autopsy was significantly associated with respondents level of education ($p = 0.01$). Respondents with secondary or tertiary education reported more positive attitude towards autopsy compared to respondents with primary level education (62.7% versus 30%, respectively). The Kikuyu ethnic group had the highest proportion of respondents with positive attitude (72.7%) while Kalenjin and Kamba respondents had the least positive attitudes

(33.3 % and 21.4% respectively) towards autopsy. Respondents from the Kamba community had a significantly different attitude compared to the Kikuyu (p = 0.002).

Table 5: Chi square tests for association between positive attitude towards autopsy and parents' characteristics

	Attitude towards autopsy			
Respondent characteristic	**Negative**	**Positive**	**Chi square**	**p value**
Age				
Below 30 years	20(48.8)	21(51.2)		Reference
31 to 50 years	22(40.7)	32(59.3)	0.61	0.44
Ethnicity				
Kikuyu	10(26.3)	28(72.7)		Reference
Luhya	6(40)	9(60)		0.51*
Luo	7(43.7)	9(56.3)		0.34*
Kalenjin	4(66.7)	2(33.3)		0.16*
Kamba	11(78.6)	3(21.4)		0.002*
Education				
Primary	14(70)	6 (30)		Reference
Secondary/ Tertiary	28(37.3)	47(62.7)	6.83	0.01
Religion				
Catholic	10(45.5)	12(54.6)	0.07	0.79
Protestant	30(42.3)	41(57.7)		

*Fishers exact test

6.1.5 Parental practice related to autopsy

Out of the 95 bereaved parents in the study, 31 (32.6%) reported that they were asked for consent to have an autopsy conducted following the death of their child. Among the 31 parents asked for consent to perform an autopsy, 9 (29.0%) consented to an autopsy while 22 (71.0%) declined.

The most commonly stated reason for consenting to an autopsy among the 9 parents was to confirm cause of death. As shown in Table 6 below, the other reasons for consenting to an autopsy included to obtain information that may influence future pregnancies and to help other children.

The reasons given by parents for declining to consent to autopsies were varied but were mainly that religion forbade autopsy (26.1%) and a feeling that diagnosis should have been established before death of the child (21.7%).

Table 6: Reasons for consenting or not consenting to an autopsy

	Frequency (%)
Reason for consenting (n = 9)	
To confirm cause of death	10(90.9)
To obtain information that may influence future pregnancies	3(27.3)
To help other children	1(9.1)
Reasons for not consenting (n = 22)	
Religion forbids	6(26.1)
Diagnosis should have been made when child was alive	5(21.7)
Patient too young	4(17.4)
Fear of mutilation of the body	3(13.0)
Culture forbids	3(13.0)
Costs	3(13.0)

As shown in table 7 below, parents who showed an adequate understanding of autopsy had higher odds of consenting to an autopsy compared to those who did not understand what an autopsy entailed (OR 2.10 95% CI 0.17 - 113.88).

Table 7: Relationship between parental knowledge and consenting to autopsy

	Provided consent for autopsy		**Odds Ratio (95% CI)**
	Yes	No	
Adequate understanding of autopsy			
No	1(20)	4(80)	1.00
Yes	10(34.5)	19(65.5)	2.10(0.17-113.88)

The parents who consented to autopsy and those who declined consent were not significantly different from each other in terms of their basic demographic characteristic. Similarly, the bio-data of deceased children whose parents consented to autopsy did not differ significantly from those of children whose parents declined to consent to autopsy.

6.1.6 Relationship between autopsy request, child and parent characteristics

6.1.6.1 Autopsy and child's bio-data

Of the 31 autopsies requested, 16 (34%) were for male children while 15 (31.4%) were for females. The odds of an autopsy request were not significantly different among male and female children (OR 0.88 95%CI 0.34 - 2.27 p = 0.77). The odds of requesting an autopsy declined consistently with increasing length of hospital stay. The proportion of autopsy requests among children who died within the day of admission was 42.9% and decreased to 36.4% for deaths occurring during day 1 to 7, 17.6% for deaths on day 8 to 14 and 22.2% for deaths occurring after day 14 (Table 8).

Table 8: Association between autopsy request and child's profile

	Autopsy requested		**Odds Ratio (95% CI)**	**p value**
Characteristic	Yes	No		
Child's sex				
Male	16(34)	31(66)	1.00	Reference
Female	15(31.3)	33(68.7)	0.88(0.34-2.27)	0.77
Length of stay (days)				
<1	6(42.9)	8(57.1)	1.00	Reference
1-7	20(36.4)	35(63.6)	0.76(0.2-3.09)	0.65
8-14	3(17.6)	14(82.4)	0.29(0.04-1.86)	0.23
>14	2(22.2)	7(77.8)	0.38(0.03-3.28)	0.40
Age at death				
<1 month	15(42.9)	20(57.1)	1.00	Reference
1-12 months	9(22.5)	31(77.5)	0.39(0.12-1.17)	0.06
13-60 months	7(35)	13(65)	0.72(0.19-2.55)	0.57

The odds of an autopsy request was highest for neonatal deaths (OR 1.00) and lowest among infants aged 1 to 12 months (OR 0.39, 95%CI 0.12 - 1.17).

6.1.6.2 Autopsy and clinical cause of death

Table 9 presents association between clinical diagnosis at death and requests for autopsy. Although there was no specific diagnosis that was significantly associated with autopsy request high percentages of patients with the following illnesses had autopsy requests: pneumonia (43.8%), neonatal sepsis (38.9%), and HIV/ AIDS (30%). The single case of malaria and all the three children with a diagnosis of NNS and asphyxia had autopsy requests.

Table 9: Association between autopsy requests and clinical diagnosis

	Autopsy requested		**Odds Ratio (95% CI)**
Clinical diagnosis	Yes	No	
Meningitis/ meningoencephalitis	2(14.3)	12(85.7)	1.00
Neonatal sepsis	7(38.9)	11(61.1)	3.81(0.53-43.6)
Pneumonia	7(43.8)	9(56.2)	4.67(0.63-53.8)
HIV/ AIDS	3(30)	7(70)	2.57(0.22-36.5)
Prematurity	3(33.3)	6(66.6)	3.0(0.25-43.1)
Pneumonia & Diarrhea	1(16.7)	5(83.3)	1.2(0.2-28.2)
Pneumonia & Malaria	2(66.7)	1(33.3)	12(0.36-764.4)
NNS & asphyxia	3(100)	0	-
Diarrhea and Dehydration	0	2(100)	-
NNS & Diarrhea	1(50)	1(50)	6.0(0.1-508.9)
Malaria	1(100)	0	-
Other	2(18.2)	9(81.8)	1.33(0.1-21.5)

6.1.6.3 Autopsy and parents' characteristics (Table 10)

There were no statistically significant association between parental characteristics and autopsy request. The odds ratio of an autopsy request among deceased children whose mothers served as study respondents was 0.88 (95% CI 0.34 - 2.28) compared to the odds of those whose fathers acted as respondents.

Table 10: Association between autopsy request and parents' characteristics

	Autopsy requested		Odds Ratio (95% CI)	p value
Characteristic	**Yes**	**No**		
Relationship with child				
Mother	15(34.1)	29(65.9)	1.00	Reference
Father	16(31.4)	35(68.6)	0.88(0.34-2.28)	0.78
Parents' age in years				
< 20-30	14(34.2)	27(65.8)	1.00	Reference
31-40	15(31.9)	32(68.1)	0.9 (0.33-2.42)	0.82
41-50	2(28.6)	5(71.4)	0.77(0.07-5.51)	0.77
Tribe or ethnicity				
Kikuyu	16(42.1)	22(57.9)	1.00	Reference
Luhya	7(46.7)	8(53.3)	1.20(0.30-4.70)	0.76
Luo	3(18.8)	13(81.3)	0.32(0.05-1.46)	0.10
Kalenjin	1(16.7)	5(83.3)	0.28(0.01-2.88)	0.23
Kamba	4(28.6)	10(71.4)	0.55(0.12-2.39)	0.37
Formal education				
Primary	4(20)	16(80)	1.00	Reference
Secondary	20(40.8)	29(59.2)	2.76(0.73-12.86)	0.099
Tertiary	7(26.9)	19(73.1)	1.47(0.30-8.10)	0.59
Religion				
Catholic	7(31.8)	15(68.2)	1.00	Reference
Protestant	23(32.4)	48(67.6)	1.03(0.34-3.40)	0.96

Ethnicity did not significantly affect requests for autopsy. The highest odds for an autopsy request was noted among respondents from the Luhya ethnic group but this was not significantly different from that of Kikuyu respondents, OR (95% CI) = 1.20 (0.30 - 4.70). For the remaining ethnic groups the odds of an autopsy request were lower than that of Kikuyu respondents but these differences were not statistically significant.

Qualitative Data

A focus group discussion was held with 11 bereaved parents

6.1.7 Demographics of bereaved parents in the focused group discussion

Of the recruited parents, 7 were female and 4 were male. The average age of the respondents was 30.3 years. The highest level of education achieved by 6 of the participants was a college education while for 5 this was a primary school education.

6.1.8 Themes emerging from the discussion

All parents understood the meaning of an autopsy i.e. procedure done to find out what caused the death of a person.

All the parents were not counseled by any health care provider regarding an autopsy on their deceased child and if they would have been asked majority would have agreed for it to be done.

Cultural or social beliefs about autopsy: Two of the parents stated that autopsies are usually done on adults due to death in circumstances such as poisoning or murder. One stated that there are no social or cultural difference between an adult and a child as regards autopsies; they can be done on both.

Majority of the parents stated that autopsies are done more in adults due to the circumstances surrounding the death of adults. According to one parent "Children are said to be holy…angels. So we can assume that God has taken an angel, they had no sin. So there is no need for an autopsy in a child".

The reasons given by the parents as to the circumstances in which an autopsy would be mandatory in a child were: If the child had been poisoned, strangled or if the tests done during the time when the child was alive are found to be negative.

The parents gave various benefits of an autopsy:

- To help with future pregnancies. One parent stated "Once you know the diagnosis it is good because the disease may have come from the parent. This would be good because you will know if there is a problem with the parent".

- Once the diagnosis is known it will also help other children, in terms of prevention of the disease.
- Research & learning for the Doctors because as they do the autopsy they get the experience and they also get to know the diagnosis.

One parent stated that the autopsy is only beneficial to the Doctors, not the parents. He said "Maybe just for research for the Doctor. For the parents, the child is already gone. It will not help".

Negative aspects of autopsies in children:

- Expensive
- Emotional for the parents as they wait for the results and as they think about the procedure that has been done on their child

One parent said, "First, it is expensive because you have to pay for it. Secondly it affects the parents emotionally. You know once you bury the child it is easier to forget but an autopsy can take up to 1 month so the more it stays the more it hurts you emotionally. And also because it takes long it also adds to the expense that is the mortuary costs."

Another stated, "If nothing is found on autopsy, it can also be bad because you can think that the child was cursed".

- May cause separation of the family or divorce if the problem is found to be genetic.

One mother stated "It can cause divorce. For example a child is done an autopsy and you find out that there are those genetic factors. Of course definitely we will divorce with my husband because many men are after children. So it can cause divorce if the parents find out there are not compatible"

6.2 Health care providers' attitude and practice towards autopsies

6.2.1 Demographic characteristics of health care providers

Of the 95 HCP recruited, nurses were a majority making up 48.4% (n=46). Interns, Paediatric residents and Paediatric consultants accounted for 21.1%, 20.0% and 10.5%, respectively. Most of the participants had worked for less than 15 years since graduating. These characteristics are described in table 11 below.

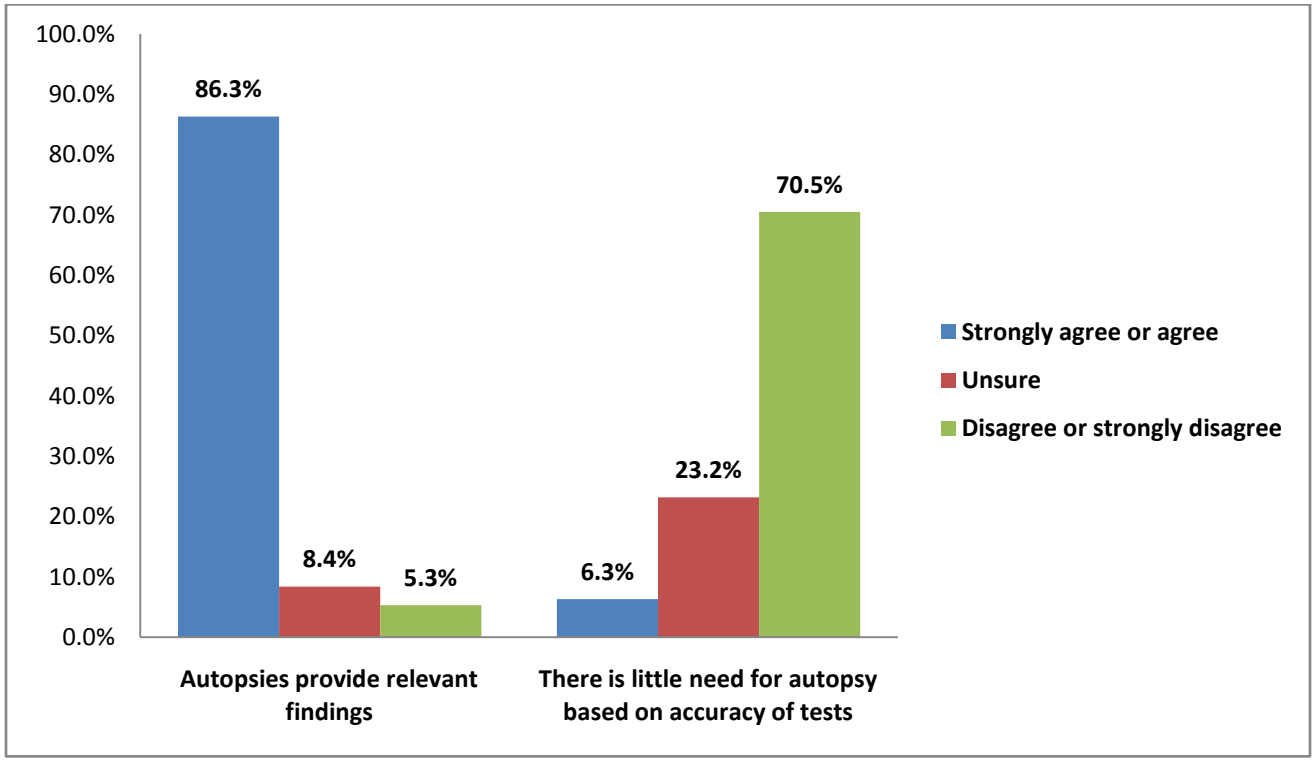
Table 11: Characteristics of health care providers interviewed

	Frequency	**%**
Designation/ cadre		
Consultant	10	10.5
Paediatric Resident	19	20.0
Medical officer intern	13	13.7
Clinical officer intern	7	7.4
Nurse	46	48.4
Years of practice since graduation		
<5	37	39.0
5-10	19	20.0
11-15	18	19.0
16-20	9	9.5
>20	12	13.6
Total	**95**	**100**

6.2.2 Health care providers' attitude towards autopsy

Most respondent agreed or strongly agreed that autopsy findings were relevant for practice. On the other hand respondents commonly disagreed or strongly disagreed that current diagnostic procedures are so accurate that there is little need for autopsies (Figure 4). Overall, based on the response to these two items a total of 66 (69.5%) health care providers showed a positive attitude towards autopsy.

Figure 4: Health care providers' response to two statements used to assess attitude



The findings of the Fishers exact test presented in table 12 below showed that health care providers' attitudes were significantly associated with their cadres. Consultants and paediatric residents (93.1%) had more positive attitudes compared to nurses (67.4) $p = 0.011$, and medical or clinical officer interns (40%), $p < 0.001$**.** Clinical experience also showed a significant influence on attitude towards autopsy. Experience of > 15 years was associated with a more positive attitude compared to < 5 years ($p = 0.002$). Reported previous counseling of parents to consent for autopsies also did not influence attitudes towards autopsies ($p = 0.09$).

Table 12: Chi square tests for association between positive attitude towards autopsy and health care providers' characteristics

	Attitude towards autopsy			
Respondent characteristic	**Negative**	**Positive**	**Chi square**	**P value**
Cadre				
Consultant/ Paediatric registrar	2(6.9)	27(93.1)	-	Reference
Medical/ clinical officer interns	12(60.0)	8(40.0)		<0.001*
Nurses	15(32.6)	31(67.4)		0.011*
Experience (years)				
< 5	16(43.2)	21(56.8)	-	Reference
5- 10	5(26.3)	14(73.7)		0.256*
11 - 15	7(38.9)	11(61.1)	0.69	0.76
>15	1(4.8)	20(95.2)		0.002*
Ever counseled parents				
Yes	14(24.1)	44 (75.9)		Reference
No	15(40.5)	22(59.6)	2.87	0.09

*Fishers exact test

6.2.2.1 Relating health care providers' attitude to childs' clinical diagnoses

Most HCP either strongly agreed or agreed that child deaths related to congenital anomalies (51.6% and 31.2%, respectively) or neonatal sepsis (36.6% and 44.1%, respectively) should be investigated using autopsy. There was considerable uncertainty (19.4%) and disagreement (35.5%) on the appropriateness of autopsy in children who died following a clinical diagnosis of HIV/ AIDS.

Table 13: Health care providers responses on appropriateness of conducting autopsies for different diagnoses

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
Asphyxia	25(26.9)	31(33.3)	15(16.1)	8(19.4)	4(4.3)
Prematurity	16(17.2)	37(39.8)	18(19.4)	18(19.4)	4(4.3)
Neonatal Sepsis	34(36.4)	41(44.1)	11(11.8)	7(7.5)	-
Congenital anomalies	48(51.6)	29(31.2)	6(6.5)	6(6.5)	4(4.3)
Pneumonia	23(24.7)	35(37.6)	20(21.5)	13(14)	2(2.2)
HIV/AIDS	18(19.4)	24(25.8)	18(19.4)	27(29.1)	6(6.5)

6.2.3 Health care providers practice towards autopsy

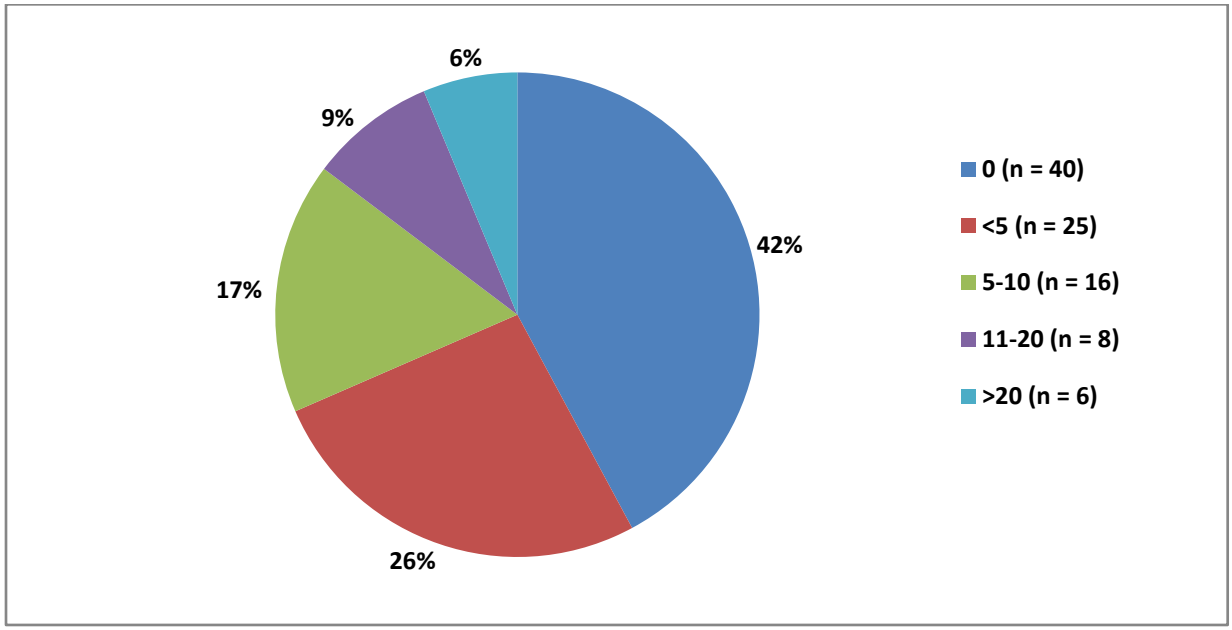
6.2.3.1 Experience with counseling on autopsy

A total of 58 (61.1%) health care providers reported to have ever counseled a parent to consent to an autopsy on their child while 37 (38.9%) had not offered such counseling. Among these 58 who had counseled parents on autopsy, 29 (50%) reported that parents had consented to autopsy on their child following the counseling and the remaining 29 (50.0%) reported that the parents did not consent to autopsy requests.

6.2.3.2 Health care providers' participation in autopsies

Most (40, 42%) reported that they had never participated in an autopsy and this finding correlated with the observation that most of the participants in the study were nurses. As shown in Figure 5 below, approximately one-quarter of the health workers reported that they had participated in less than five autopsies.

Figure 5: Number of autopsies that health care providers reported to have participated in



6.2.3.3 Health care providers: Factors affecting failure to obtain consent

Health care providers identified the lack of formal training in obtaining consent and the failure to avail autopsy results in a timely manner as the main barriers to obtaining consent to conduct autopsies. Other common causes were lack of time to counsel parents (15.8%), presumption that such requests would upset grieving parents (15.8%) and also impose additional costs on families (12.6%).

Table 14: Factors associated with failure to obtain consent

	Frequency	%
Request will upset the parents	15	15.8
No formal training in obtaining consent	21	22.1
Lack of time to counsel parents	15	15.8
Autopsy results no available in a timely manner	19	20.0
Fear of litigation	1	1.1
Autopsy will delay funeral arrangements	5	5.3
Costly for the family	12	12.6

7.0 DISCUSSION

The autopsy is the accepted gold standard for determination of cause of death (1). Despite the crucial role that it plays in the development of the science and practice of medicine, autopsy rates have been declining throughout the world (6). The reasons for this decline are varied and complex. One of these reasons is the attitude of the public and health care providers towards the autopsy.

Our study sought to determine the level of knowledge regarding autopsy in bereaved parents, their attitudes, and practice among those who were asked to consent to an autopsy. We also sought to describe the attitude and practice of health care providers towards autopsy in children.

7.1. Bereaved parents

7.1.1 Demographic characteristics of bereaved parents

Our study recruited 95 bereaved parents. The modal age group was 31-40 years with an average age of 31.8 years. All parents had attained formal education with 50.6% having attained secondary education. This could be attributed to the fact that the study was carried out in a hospital in an urban area. According to the KDHS 2008-2009, educational attainment varies with place of residence with respondents in urban areas being more educated than their rural counterparts. 53% of males in urban areas have completed secondary school or higher, compared with 22% in the rural areas. Among women, 45% of those in urban areas have completed secondary education or higher, compared with only 14% of their counterparts in rural areas (13).

Most parents were Christians with 74.7% being Protestant and 23.2% Catholic. Our study did not recruit any parents of the Muslim faith. This could possibly be explained by the fact that although we were able to capture most parents 48 hours after death of their child, most Muslim parents would have buried their children within that time period as per their faith regulations.

7.1.2 Parental knowledge of Autopsy

Among the 95 parents recruited in the study, 79% had good knowledge of the meaning of an autopsy. In contrast, the study carried out by Oluwasola et al in Nigeria found that only 42% of relatives of deceased demonstrated satisfactory knowledge of autopsy (6). In the Nigerian study 94.6% of those who were able to explain autopsy had 7 to 12 years of education. This association with level of education was statistically significant ($x^2 = 59.8$, $P < 0.001$). In our study, all parents had attained formal education with 50.6% having attained secondary education. Despite this good knowledge on autopsy, majority of parents asked to consent declined. This could be due to cultural and religious beliefs.

7.1.3 Parents attitude towards autopsy

In our study, 55.7% of bereaved parents had a positive attitude towards autopsy compared to 44.3% who had a negative attitude. Positive attitude towards autopsy was significantly associated with respondents level of education ($p = 0.01$). Respondent with secondary or tertiary education reported more positive attitude towards autopsy compared to respondents with primary level education. Respondents from the Kikuyu ethnic group had more positive attitude towards autopsy (72.7%) compared to other ethnic groups. The attitude of respondents from the Kamba ethnic group were significantly different from those of the Kikuyu ($p = 0.002$) with the Kamba having a more negative attitude to autopsy. This could possibly be explained by the cultural differences between these two ethnic groups.

This shows a similar trend to the findings of Oluwasola et al, where 73.3% of the family members approved of performing autopsy as part of medical care (6). 32% of relatives indicated they would consent to autopsy on themselves compared to 57.9% in our study. This difference could possibly be explained by one of the themes that came up during the focused group discussion; that majority of parents felt that autopsies are done more in adults than children due to the circumstances surrounding their death. In the Nigerian study, of the relatives that expressed unwillingness to consent to autopsy, 82% were Muslims. This is similar to the religious beliefs of the Muslim faith in Kenya in which autopsies are forbidden.

7.1.4 Parents practice towards autopsy

A total of 31 parents were asked to consent to an autopsy on their deceased child; 9 (29.0%) consented to an autopsy while 22 (71.0%) declined to consent. This differs from the findings of McHaffie et al where 62% of the 58 parents asked to consent to an autopsy on their deceased neonate agreed, with 38% declining (24). This difference could possibly be related to the cadre of health care provider seeking consent, with greater success seen in those counseled by a neonatologist (24).

The most commonly stated reason for consenting to an autopsy among the 9 parents in our study was to confirm cause of death. This was similar to findings by McHaffie et al where the main reason cited by parents who consented to autopsy was to obtain answers to their questions, more specifically, confirmation of the diagnosis (24).

In our study there was no statistical significance between parents' practice regarding autopsy and their sociodemographic characteristics, i.e.; age (p=0.70), ethnicity (p=0.76), education (p=0.099) and religion (p=0.96)). Although parents who showed an adequate understanding of autopsy had higher odds of consenting to an autopsy compared to those who did not understand what an autopsy entailed. This lack of significance could possibly be explained by the fact that the number of parents who were actually counseled on consent to autopsy in our study was small (n = 31).

The reasons given by parents who declined to consent to an autopsy were mainly that religion forbade autopsy and a feeling that diagnosis should have been established before death of the child. This is despite the fact that from what is known, autopsy is not forbidden in the Christian faith. Thus other factors may play a part in the refusal to consent (e.g. cultural).
These findings show some similarity to those of Lishimpi et al (2), who identified the main reasons for parents refusal to consent for necropsy were that 43% felt that the diagnosis should have been made when the child was alive, 26.5% refused because a death certificate had already been issued and in 8.6%, ancestral spirits forbade the mutilation of dead bodies. The study by McHaffie et al found that the main reasons for declining an autopsy were dread of the child

being mutilated or subjected to further invasion and having no further questions that needed to be answered (25).

A similar study in Nigeria by Oluwasola et al looked at the reasons for which family members would refuse to give consent for autopsy on a deceased relative (6). The highest ranked reason was fear of mutilation of body. Others were concerns about delaying the funeral, objection expressed by the patient before death, and deceased considered too young or too old. The difference in findings could possibly be explained by the fact that the Nigerian study was done on relatives of the deceased (relation to the deceased was not specified) while our study was done on the parents of the deceased child.

Focused Group Discussion

Majority of parents understood the meaning of an autopsy though none had been counseled by a health care provider on consent to an autopsy. These findings are similar to those of the quantitative arm of the study.

The parents expressed that autopsies are usually done on adults and not on children except in circumstances such as poisoning or if investigations done do not reveal the diagnosis. This could explain the low uptake of autopsy by bereaved parents despite good knowledge.

7.2 Health care providers

7.2.1 Attitude towards autopsy

In our study 69.5% of health workers showed a positive attitude towards autopsy compared to 31.5% who showed a negative attitude. This finding shows a similar trend to the study by Oluwasola et al in which 95% of doctors approved of the practice of autopsy (6).

In our study, attitude was significantly associated with health care providers' cadres: Consultants and paediatric residents had a more positive attitude compared to nurses ($p = 0.011$), and medical or clinical officer interns ($p < 0.001$)**.** Experience of > 15 years was associated with a more positive attitude compared to < 5 years ($p = 0.002$).

This was similar to studies done in developed countries: Van Mater et al looked at physicians' attitudes regarding neonatal autopsy (20). They found that increased overall importance of autopsy was seen with advancement in staff position as well as experience in requesting for consent. Interns and residents rated the overall importance of neonatal autopsy to be very important in 46% and 50% of cases, respectively, compared with 83% and 82% of ratings from fellows and attending physicians, respectively. Hooper at al investigated the nature of physician attitudes about autopsy and found that one of the most crucial factors influencing attitudes is the physician's level of experience with autopsy in training and practice (23). Among other interesting results was that strength of belief in autopsy relevancy correlated significantly with greater prior exposure to the autopsy.

7.2.2 Practice towards autopsy

Our study revealed that 61.1% of health care providers reported to have ever counseled a parent to consent to an autopsy request on their child with 50% of the parents counseled consenting.

The main reasons given by health care providers for not obtaining consent for autopsy were lack of formal training in obtaining consent and the failure to obtain autopsy results in timely manner. This is similar to the findings of Oluwasola which found that doctors considered difficulty in obtaining consent from relatives of deceased as the major reason for the decline in the rate of autopsy (6). Other reasons given included administrative bottlenecks when requesting an autopsy and delay in obtaining the autopsy report.

8.0 STUDY LIMITATIONS

1. The study was dependent on the willingness of the parents and health care providers to participate in the study, thus sampling was not random.

2. The study largely depended upon the timely identification of the bereaved parents before they left the hospital.

3. Due to the small number of parents who were counseled on autopsy, the study has limited power to conclude on correlates between practice and bereaved parents sociodemographic characteristics.

4. The study was conducted in an urban setting and the views of parents in the rural areas may be different from their urban counterparts.

5. Our study did not recruit any parents of the Muslim faith, limiting how much we can generalize our findings to the greater Kenyan population, a large percentage of which is Muslim.

9.0 CONCLUSIONS

Bereaved parents had adequate knowledge as regards autopsy (79% of those recruited) with a positive attitude being significantly associated with the level of education. Majority (67.4%) of parents were not asked to consent to an autopsy on their deceased child. Of those asked to consent majority declined mainly due to religious beliefs while those who agreed did so to confirm cause of death. Parents with a higher understanding of autopsy were more likely to consent.

Health care providers had a positive attitude to autopsy which was significantly associated with their cadre and years of experience. Consultants and paeadiatric residents had a more positive attitude compared to interns and nurses. Clinical experience also showed a significant influence on attitude towards autopsy. The main reasons given for not obtaining consent for autopsy were lack of formal training in obtaining consent and the failure to obtain autopsy results in timely manner.

10.0 RECOMMENDATIONS

Bereaved parents need to be counseled on the need for autopsy on their deceased child as well as counseling around potential barriers to consent including religious beliefs.

Health care providers should be trained on how to counsel parents after death of their child as well as on how to request for an autopsy. Their participation in autopsies should also be encouraged.

Further qualitative and quantitative research, with a larger number of participants, should be performed to further describe bereaved parents and health care providers', attitude and practice towards autopsy in our setting.

11.0 APPENDICES

11.1 Appendix 1: References

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11.2 Appendix 2: Tables

Table 1: Classification of concordance between diagnosis before death and at autopsy*

CLASS	DESCRIPTION
I. A	Diagnosis that, had it been detected before death, would probably have led to change in management that might have resulted in cure or prolonged survival
B	Diagnosis with significant implications for future genetic advice
II.	Diagnosis that, had it been detected before death, would probably not have led to change in management or survival because: ➢ No appropriate therapy was available at the time ➢ Appropriate therapy was given even though the diagnosis was unknown at the time ➢ Patient had acute cardiopulmonary arrest that was appropriately managed, but patient did not survive for definitive management ➢ Patient had "do not resuscitate" status
III.	Diagnosis that may or may not have been related to main disease process and was contributory cause of death
IV.	Diagnosis unrelated to outcome and may or may not have affected eventual prognosis of patient
V.	Complete concordance between diagnosis before death and findings at autopsy

***** Modified from Kumar et al (10) and Goldman et al (3)

TABLE 2: Trends in early childhood mortality rates in Kenya

YEAR	UNDER 5 MORTALITY	INFANT MORTALITY RATE	NEONATAL MORTALITY RATE
1998	112	74	25
2003	115	77	35
2008	74	52	31

11.3 Appendix 3: Questionnaires

QUESTIONNAIRE ON KNOWLEDGE, ATTITUDE AND PRACTICE OF BEREAVED PARENTS TO AUTOPSIES IN CHILDREN UNDER 5 YEARS AT KENYATTA NATIONAL HOSPITAL

QUESTIONNAIRE SERIAL NUMBER ☐

SECTION 1: CHILDS BIODATA

1. AGE AT DEATH :
   1 = <1 month (a) Term (b) Preterm
   2 =1-12months
   3= 1-5 years

2. SEX: 1=MALE 2= FEMALE

3. STAYS IN HOSPITAL (DAYS):
   1 = <1 2 = 2-7 3 =8-14 4 =>14

4. CLINICAL DIAGNOSIS AT TIME OF DEATH:
   1 = Neonatal Sepsis: (a) Clinical (b) Proven
   2 = Prematurity
   3 = Perinatal Asphyxia
   4 = Congenital Abnormality
   5 = Pneumonia
   6 = Diarrhoea and Dehydration
   7 = Malaria
   8 = HIV/AIDS
   9 = Others (specify……..…)

5. Autopsy requested: 1 = YES (proceed to Qs 6) 2 = NO

6. If Yes, was autopsy done 1 = YES 2 = NO

SECTION 2: DEMOGRAPHIC DATA OF RESPONDENT

7. Respondent 1 = MOTHER 2=FATHER

8. Age (years) of primary respondent
   1= <20 2= 21-30 3 =31-40 4= 41-50 5 =51-60 6= 61-70

9. Ethnic group of primary respondent
   1 = Kikuyu 2 = Luhya 3 = Luo 4 =Kalenjin 5 = Kamba

   6 = Other (specify……..)

10. Level of education of primary respondent 1 =Primary 2 = Secondary 3 = Tertiary

11. Religion of primary respondent: 1= Catholic 2 = Islam 3=Protestant

4 = Other (specify……..…….)

SECTION 3: KNOWLEDGE ON AUTOPSY

12. What do you understand by autopsy?

(TICK ONE OR MORE STATEMENTS THAT BEST FITS RESPONDENTS' ANSWER)

A	Autopsy is wholly an academic exercise	
B	Autopsy involves examination of all the internal and external organs of a corpse.	
C	Autopsy is performed to determine cause of death.	
D	Autopsy enables monitoring of competence of medical staff.	
E	Autopsy can provide emotional assurance for relatives of deceased.	

SECTION 4: PRACTICE ON AUTOPSY

13. Were you asked to consent for autopsy on your child?
1=YES (Proceed to Qs 14) 2 = NO (Proceed to Qs 17)

14. Did you consent to an autopsy on your child?
1 = YES (Proceed to Qs 15) 2 = NO (Proceed to Qs 16)

15. What was your reason for agreeing to an autopsy?
1 = To confirm the cause of death
2 = To help other children
3 = To obtain information that may influence future pregnancies
4 = To know if I (mother) had done anything to cause the death
5= Other (specify……..…….)

16. What was your reason for declining an autopsy?
1 = Diagnosis should have been made when child was alive
2 = Fear of mutilation of the body
3 = Patient too young
4 = Delay funeral arrangements
5 = Cost
6 = Culture forbids
7 = Religion forbids
8=Other (specify…….……)

17. If you would have been asked what would have been your answer?
1 = YES
2 = NO (Proceed to Qs. 18)

18. Why would you not have consented to an autopsy?
1 = Diagnosis should have been made when child was alive
2 = Fear of mutilation of the body
3 = Patient too young
4 = Delay funeral arrangements
5 = Cost
6 = Culture forbids
7 = Religion forbids
8=Other (specify…….……)

SECTION 5: ATTITUDE ON AUTOPSY

		Agree	Not sure	Disagree
19	I approve of the practice of autopsy			
20	Autopsy is of no benefit to the Kenyan society			
21	There is need to improve public awareness on autopsies			
22	Should a reason arise, would you consent to an autopsy procedure being performed on you?			
23	If, No, why? …… ……			

ATTITUDE OF HEALTH CARE WORKERS IN KENYATTA NATIONAL HOSPITAL TOWARDS NEONATAL AUTOPSIES

QUESTIONNAIRE SERIAL NUMBER ☐

SECTION 1: DEMOGRAPHIC DATA

1. Designation/Cadre ☐
   1 = Consultant
   2 = Paediatric Resident
   3= Nurse

2. Number of years of work since graduation ☐
   1 =<5 2 = 5-10 3 = 10-15 4 = 15-20 5 = >20

SECTION 2: EXPERIENCE ON AUTOPSIES

3. Have you ever counseled a parent(s) to consent to an autopsy request on their child? ☐
   1 = Yes (proceed to Qs 4) 2 = No (proceed to Qs 5)

4. What was the response? 1 = Consented 2 = Did not consent

5. What was the main reason for not counseling parents on autopsy?
   ……
   ……

6. The number of autopsy procedures I have observed or participated in as a student, nurse, resident or consultant is approximately? ☐
   1 = 0 2 = <5 3 = 5-10 4 = 11-20 5 = >20

SECTION 3: ATTITUDE ON AUTOPSIES
(NOTE: SA – STRONGLY AGREE SD – STRONGLY DISAGREE)

7. Autopsies are capable of providing relevant findings that could change my future clinical practice
   SA SD
   1 2 3 4 5

8. Current diagnostic procedures are so accurate that there is little need for autopsies
   SA SD
   1 2 3 4 5

9. Autopsies are important in the following clinical causes of death (Tick)

	SA 1	2	3	4	SD 5
Asphyxia					
Prematurity					
Neonatal Sepsis					
Congenital anomaly					

	SA 1	2	3	4	SD 5
Pneumonia					
HIV/AIDS					

10. What are the factors affecting failure to obtain consent for autopsies in children under 5 years in KNH?
    1 = Request will upset the parents
    2 = No formal training in obtaining consent for autopsy
    3 = Lack of time to counsel parents
    4 = Autopsy results no available in a timely manner
    5 = Fear of litigation
    6 = Autopsy will delay funeral arrangements
    7 = Costly for the family
    8 = Other (specify……)

11.4 Appendix 4: Focus Group Discussion guide

FOCUS GROUP DISCUSSION INTERVIEW GUIDE

Participants

Initials	Age (Yrs)	Sex (M/F)	Education Level	Occupation/Social Position
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

Preamble

There is concern that autopsy rates in children are low and therefore the actual cause of death is not established. We would like your help to find out the reasons for this low rate.

1. What do you understand by the word autopsy?
2. What do people in your community (social or cultural) believe about autopsies?
3. On whom should autopsies be performed?
4. Under what circumstances is an autopsy mandatory in a child?
5. What are the benefits of an autopsy?
6. What are the negative aspects of autopsies in children?

11.5 Appendix 5: Consent form for bereaved parents

Dear **Parent/Guardian**,

I am a postgraduate student at the University of Nairobi, College of Health Sciences, pursuing studies leading to specialization in Paediatrics and Child Health. I wish to request for your permission, for you to participate in a study that will form part of my degree work.
The study will involve requesting you to answer some questions from a structured questionnaire. These will be recorded (written and audio), and analyzed for research purposes only. I would also request your permission to audio-record the interview. Your identity will be kept confidential.

Benefits – The results of this study will be used to highlight the factors affecting low rate of autopsies in children and the information gained will guide policy makers and other stakeholders on how to best improve delivery of services so as to reduce child mortality.

Risks - no experimental investigations or products will be employed in this study. No medical procedures will be undertaken to you as the study participant and therefore there are no foreseeable risks to your health or well being by participating in this study.

Your participation is purely voluntary, there is no monetary gain and you may withdraw from the study at any stage, without any penalty. It will not cost you anything to participate in this study.

You are free to ask any Questions about my study if you require any clarification.

Contact of Investigator: **Dr. Edel Karau**
Dept of Paediatrics and Child Health
College of Health Sciences
Tel 0722 964 003

I would therefore appreciate your consent by signing here below:

I, **Dr Edel Karau**, confirm that I have explained the relevant parts of the study to the participant.

Signed: _____ Date_____

I, **the participant**, confirm that I have understood the relevant parts of the study and do hereby give consent to participate.

Signed: _____Date_____

11.6 Appendix 6: Consent form for Health care providers

Dear **Sir/Madam**,

I am a postgraduate student at the University of Nairobi, College of Health Sciences, pursuing studies leading to specialization in Paediatrics and Child Health. I wish to request for your permission, for you to participate in a study that will form part of my degree work. The study will involve requesting you to answer some questions from a structured questionnaire. Your identity will be kept confidential.

Benefits of this study include highlighting the factors affecting the low rate of autopsies in children and the information gained will guide policy makers and other stakeholders on how to best improve delivery of services so as to reduce child mortality.

Risks - There will be no risks to you during the study. There will be no invasive procedures carried out in the study that may harm you.

Your participation is purely voluntary, there is no monetary gain and you may withdraw from the study at any stage, without any penalty. It will not cost you anything to participate in this study

You are free to ask any Questions about my study if you require any clarification.

Contact of Investigator: **Dr. Edel Karau**
Dept of Paediatrics and Child Health
College of Health Sciences
Tel 0722 964 003

I would therefore appreciate your consent by signing here below:

I, **Dr Edel Karau**, confirm that I have explained the relevant parts of the study to the participant.

Signed: _____ Date_____

I, **the participant**, confirm that I have understood the relevant parts of the study and do hereby give consent to participate.

Signed: _____Date_____