

**KNOWLEDGE, ATTITUDE, PRACTICE AND BARRIERS TO SERVICE  
DELIVERY OF PAEDIATRIC PALLIATIVE CARE AMONGST HEALTH  
CARE PRACTITIONERS AT KENYATTA NATIONAL HOSPITAL**

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**DECLARATION**

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

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## **DEDICATION**

To God almighty for equipping me with the strength, wisdom and resilience to carry out this work in the midst of a pandemic.

To all the health care practitioners whose involvement, and contributions made this study possible.

To my family for their patience, love and support.

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## **ABBREVIATIONS**

<b>BCW</b>	Behaviour Change Wheel
<b>COM-B</b>	Capability, Opportunity, Motivation and Behaviour
<b>FGD</b>	Focused Group Discussion
<b>HCPs</b>	Health Care Practitioners
<b>HOD</b>	Head of Department
<b>ICU</b>	Intensive Care Unit
<b>KAP</b>	Knowledge, Attitude and Practice
<b>KII</b>	Key Informant Interview
<b>KNH</b>	Kenyatta National Hospital
<b>LMICs</b>	Lower- and Middle-Income Countries
<b>NBU</b>	Newborn Unit
<b>PC</b>	Palliative Care
<b>PEU</b>	Paediatric Emergency Unit
<b>PICU</b>	Paediatric Intensive Care Unit
<b>PPC</b>	Paediatric Palliative Care
<b>PRU</b>	Paediatric Renal Unit
<b>UON</b>	University of Nairobi
<b>WHO</b>	World Health Organization

## **OPERATIONAL DEFINITIONS**

**Attitude** - A settled way of thinking or feeling about something. In this study, refers to attitude of HCPs towards a child with chronic, complex and/or life-threatening condition.

**Health Care Practitioners** - All cadres of health care workers registered by their respective professional bodies.

**Knowledge** - The information, understanding and skills that one gains through education or experience. In this study it will involve knowledge of paediatric palliative care.

**Life Limiting Condition** - Condition for which there is no reasonable hope of cure and from which a child or young person will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and guardians.

**Life Threatening Condition** - Condition for which curative treatment may be possible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

**Practice** - The actual application or use of an idea, belief or method, as opposed to theories relating to it.

**Resident** - A medical graduate engaged in specialized practice under supervision in a hospital.

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## ABSTRACT

**Background:** Paediatric palliative care (PPC) services requires a broad multidisciplinary approach to provide comprehensive high-quality care for children. This can be achieved by having appropriate policies, adequate drug availability and educating the health care practitioners (HCPs). Despite having integrated hospice-palliative care services into mainstream service provision, there is scarcity of data on uptake, utilization, provision and barriers to PPC services delivery in Kenya.

**Objectives:** **Primary objectives** were to assess knowledge, attitude and practice (KAP) of PPC amongst health care practitioners at Kenyatta National Hospital (KNH) and to explore barriers to PPC service delivery in KNH paediatric wards. **Secondary objective** was to determine factors associated with KAP of paediatric palliative care at KNH.

**Methods:** Mixed-methods. Cross sectional study amongst HCPs. Quantitative approach was conducted by filling out a questionnaire to assess the level of KAP of PPC amongst HCPs at KNH. Through the qualitative approach, interviews were conducted with HCPs to explore factors affecting the PPC service delivery at KNH paediatric wards.

**Data analysis:** Quantitative data obtained were exported to R and coded for statistical analysis. Median and interquartile ranges were used to summarize HCP knowledge, attitude and practice scores of PPC at KNH (primary objective). Multivariable logistical regression were used to determine factors associated with KAP of PPC at KNH (secondary objective). Qualitative data were analyzed using N-Vivo version 10 after verbatim transcription, translation and cleaning. Thematic content analysis was done to identify recurring themes. Data from the two research paradigms were integrated.

**Results:** From the 233 nurses and residents, 40(17.2%) had good knowledge, 97(41.6%) had good practice and all participants had favorable attitude towards PPC. Males and residents were positively associated with good knowledge of PPC. Residents had a 35% likelihood of having poor practice of PPC. Main barriers to PPC service delivery included deficient knowledge, stigma, bureaucracy, poor and late referral processes and staff shortages.

**Conclusions:** The HCPs had poor knowledge and practice, but their attitude towards PPC was favorable. The recommendations are for the different cadres and both genders to work together to ensure PPC services are initiated in a timely fashion and appropriately; on job continuous medical educations and trainings to bridge the gap of poor practice and deficient knowledge as well as demystifying the stigma surrounding palliative care. To expand the human resource as well as streamline referral processes and workplace bureaucracy.

## **CHAPTER 1: INTRODUCTION**

Palliative care (PC) defined as strategies that improves the quality of life of patients and their families when facing life-threatening or life-limiting illness. It averts suffering by timely and accurate identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”(1). This definition is philosophical(2), as it invokes values of being patient-centered, comprehensive and multi-disciplinarity, aimed at guiding action and improving practice(3,4). The core mandate of PC improving quality and meaningfulness of life for patients and their families. Thus, being of benefit to all patients irrespective of their disease stages(5).

Paediatric palliative care defined as care for children with life-limiting and life-threatening conditions. It employs an active and total approach to care from diagnosis, throughout the child’s life, death and beyond. It entails enhancing the patients quality of life and supporting them and their family, physically, emotionally, socially and spiritually. It encompasses symptom management, care through death and beyond(1,6). For palliative care to have any impact it requires a broad multidisciplinary approach that partners with families and utilizes community resources, therefore care in resources limited regions can successfully be provided in all levels of care(7).

Pain relief is a component of palliative care and it is regarded as a human right (8–10). Inadequate pain control and insensible suffering jeopardizes fundamental health rights and protections. Governments are under obligations to provide essential medicines which include opioid analgesics (11).

World Health Assembly (WHA) placed value on primary health care and community/home-based care as a strategy of improving access to palliative care in health systems(12).

In order to integrate palliative care into society and alter experiences, the following must be addressed:  
a) policies b) drug availability c) education of HCPs and d) implementation of services at all levels of care in accordance to the culture, disease demographics, socioeconomics and the health care system(13).

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1. African Perspective of Palliative Care**

Annually, roughly 40 million people are in need of palliative care, 78% of whom live in low- and middle-income countries (LMICs). LMICs accounting for 98% of palliative need for children with 50% of them living in Africa (14). By 2011, only 20 countries had integrated PC services, 42% had no PC services and 32% having isolated PC service(15).

An overview of PC development shows that, only South Africa, Tanzania, Uganda and Kenya, were reported to have PC integrated into the health plans(16). Across Africa poverty, poor knowledge, inadequate human resource are among the cited barriers to optimal palliative care delivery(12), others are under-utilization of PC services(17), inept pain diagnosis and treatment(18,19), lack of training and expertise (20), and ethical issues(21).

### **2.2. Kenyan Perspective of Palliative Care**

Kenya is considered a level 4a country(15), in which hospice-palliative care services have been integrated into mainstream service provision. The Diana Princess of Wales Memorial Fund, True Colors Trust and Kenya Hospices and Palliative Care Association (KEHPCA) in partnership with Ministry of Health (MoH), have ensured palliative care is currently available in 20 of Kenya's 47 counties(22,23). These centres consists of two mission hospitals and 41 government hospitals (24). In 2016, the palliative care units served 30,000 patients and had more than 220 trained health care professionals(22). The trained HCPs are responsible for mentoring and supervising other HCPs(25).

This partnership led to the development of guidelines with the aim of streamlining the provision of PC in Kenya (26).

Education and training significantly impact the success, enrollment, guardianship and sustainability of palliative care(13). This has been achieved by integrating palliative care teaching in the pre-service curricula. The Nursing Council of Kenya offers palliative care as part of the curriculum, while pain management was added to the pharmacy curriculum(23). KEHPCA has been offering training to medical students from the University of Nairobi, prior to their graduation(27).

### **2.3. Paediatric Palliative Care (PPC)**

Roughly 26% of the global population is made up of children(<15 years), rising up to 40% in low-income areas(28).

Global estimate of PPC need at end of life is more than seven million(14). Out of these, 49% are living in LMICs(14). Majority of the children(68%) will die from perinatal conditions, around 16% from congenital anomalies and Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) and only a small number(3%) from cancer. Thus, patients enrolled to PPC will present with other life-threatening/life-limiting illnesses and not malignant tumors(29,30).

In Kenya, approximately 680,000 children are in need of generalized palliative care, with over 260,000 in need of specialized care and only 0.21% of the need being met(26). Currently KEHPCA reports 18 health care facilities are equipped to offer palliative care services to children across Kenya(27).

Programs that prioritize community outreach and public education are postulated to be essential for excellence and sustainability(31).

The Kenyatta National Hospital (KNH) meets the minimum standards of PPC in a tertiary care center. This comprises of smooth and continuous transitions within departments, accessible PPC experts and a multi-disciplinary care team to address all aspect of care(31).

#### 2.4. Categories of Life-Limiting and Life-Threatening Conditions

Disease trajectories have been fundamental in the evolution of a classification system of patients with life-limiting and life-threatening illnesses that would utilize PPC services(Table 1)(6).

**Table 1. Life-limiting/threatening illnesses**

1	<b>Curative treatment attainable but can fail.</b> Advanced malignant tumor, irreversible organ failure, complex and acquired heart disease, severe malnutrition, tuberculosis.
2	<b>Inevitable untimely death.</b> Renal failure on dialysis, HIV/AIDS on treatment, Cystic fibrosis and neurodegenerative conditions.
3	<b>No curative treatment available.</b> Down syndrome having a complex and severe congenital heart lesion, Batten disease and renal failure(no dialysis).
4	<b>Irreversible and non-progressive with health complications that can lead to untimely fatality.</b> Fetal alcohol syndrome, birth asphyxia, Down syndrome, severe cerebral palsy and sickle cell anemia.



**Table 2. Wood et al added two categories(32),**

5	Seriously ill neonates.
6	Family member after the loss of a neonate.

Notes: Exercise caution when assessing patients using diagnosis only, as not all patients who present with the above listed conditions are candidates for palliative care. There are three phases encountered: a) stable phase, where patients have few symptoms but suddenly deteriorate or die prematurely, b) phase of advancing and progressive disease and c) chronic phase, where non-progressive conditions have periods of remission and of symptomatology. Therefore, explore symptoms exhibited in the last year of life to correctly classify patients prior to enrolment into PC programs. Early integration into PPC is the standard of care for patients with life-threatening conditions as it empowers the patient and their families to make decisions that are in-keeping with their values and beliefs concerning their care(33).

## **2.5. Supporting Human Resource**

Strengthening the skills and awareness of PC amongst the HCPs is pivotal to improving access and utilization care. Specialist training in PC is valuable, but all HCPs should possess basic knowledge of

good pain management and PC principles. In spite of this, most HCPs receive no or limited training in PC prior to their deployment for service delivery. Therefore, continuous training while in service is paramount for those already delivering care(12).

## **2.6. Knowledge, Attitude, Practice(KAP) and Perceptions of PC Among HCPs**

The HCP's knowledge, beliefs, experiences and attitude are essential for successful service delivery as they influence approach and behavior during assessment and management of patients(34).

Any unnecessary torment by treatable symptoms is sustained by the lack of knowledge of PC, which emphasizes the need for educating and offering adequate training for HCPs and caretakers(35).

In a study conducted in Ukraine, 578 healthcare workers were interviewed to assess their awareness of paediatric palliative care. Approximately 25% of the respondents did not know the meaning of paediatric palliative care. The main cohort for PPC delivery was considered to be patients with cancer (71.5%), and not with incurable chronic diseases (54.8%). Only 59.7% of respondents knew that PC should begin with the diagnosis of an incurable disease, and not at the end of life. About half (52.6%) of them knew that the relatives of seriously ill children are candidates for PC. The majority of respondents recognized the lack of their knowledge of paediatric palliative care (85.8%). Almost all respondents (94.5%) expressed their desire to receive proper knowledge of PPC(36).

In Lebanon, a survey amongst 3757 HCPs showed that about 96% of physicians and 93% of nurses correctly identified PC goals. About 94% to 99% were of the opinion that critically ill patients and their families should be enlightened of their diagnosis and prognosis. However, at best 19% of HCPs frequently practiced this(37). Another Lebanese study on PC revealed significant differences between HCPs in surgical and medical specialties, with regards to flare-up and concerns from families, patients'

perception and questions. There was statistical association between knowledge scores with practice degree and scores. They reported positive association between practice scores with caring for critically ill patients, continuous education in PC, and scores in attitude and knowledge. Despite this HCPs from the intensive care unit(ICU) and oncology wards scored lower in their practice than other specialties(38).

A survey conducted in Iran including 117 nurses showed that 19% had good knowledge, 85% had favorable attitude while 6% had good practice towards PC. Nurses practice of PC was significantly associated with level of education and the ward. Those posted in the ICUs and those with master degrees had better PC practice. The level of education was meaningfully associated with the nurses' attitude towards PC(39).

Of 96 nurses interviewed in a Palestinian study, 20.8% had good general knowledge of PC, those trained in PC were 59.4%, while 6.2% of the respondents having good attitude towards PC. Their PC knowledge was significantly associated with work experience, training and qualification(34).

A survey done by Oakley regarding palliative care teams, to comprehend the HCPs understanding of their roles, confidence levels and knowledge when caring for PC patients. The outcome called attention to some misconceptions but illustrated the staffs' confidence in their expertise, except discharge planning, in spite of the fact that majority of the HCPs had not undergone training in PC. It emerged that the HCPs were more confident caring for terminal patients than they were verbalizing about death and dying or dealing with sorrowful relatives. Trained HCPs were self-assured of their expertise and attributed this to training in PC(40).

In a survey conducted in Saudi Arabia to inform on PC knowledge and attitudes of health care personnel and any influencing factors amongst 395 nurses from 19 nationalities revealed a knowledge deficiency and modest attitude regarding PC. The scores were remarkably influenced by work experience and training in PC. It became apparent that PC integration into health care in the nurses' country of origin was an important factor(41).

In a survey conducted among 365 HCPs Ethiopia showed that 30.5% possessed good knowledge and 76% possessed favorable attitude regarding PC. Knowledge among the nurses was found to have positive association with training in PC and their ward allocation (surgery/medicine). Attitude was notably linked to qualifications, institution, in-service training in PC and work station in medical wards. Nurses in non-governmental hospitals possessed 71.5% likelihood of having unfavorable attitude regarding PC than those in governmental hospitals. The participants highlighted that delays evolved into end-stage diagnosis and this attributed to the poor practice scores(76.2%). They also reflected highly on medical illnesses and spiritual aspects when nursing critically ill patients(42).

### **2.7. Barriers to PPC Service Delivery**

An American article categorized these barriers at different levels as follows: a) policy - inadequate funding, b) health system - insufficient programs and personnel, c) organizational - drawbacks with PC integration into pre-existing models of care, and d) individual - deficiency with regards to PPC knowledge, unsettling death/dying talks and cultural controversies between patients, family members and HCPs(43).

In Switzerland a qualitative survey was carried out amongst HCPs posted in cancer centers to explore comprehension of and attitudes towards PPC from their perspective. Majority of the respondents linked PPC with non-curative management. Stigma emerged as a major hinderance to service delivery especially to families. To overcome the stigma, respondents utilized synonyms like supportive or comfort care. Though some HCPs preferred using PC but emphasized on the need for an optimistic “word of mouth”(44).

Barriers to PC encountered by HCPs caring for terminally ill children were investigated among 117 nurses and 81 physicians in California, it revealed that roughly half of the participants outlined 4 main barriers, which included, unpredictable prognosis (55%), denial within the family concerning incurable diagnosis (51%), time restrictions (47%), and communication barriers (47%)(45).

Twamley et al surveyed an established PPC team, in the United Kingdom among HCPs deployed in a tertiary care facility. They analyzed knowledge, awareness and attitudes, with an objective of establishing interventions to boost patient linkage to PC services. The participants displayed exemplary knowledge of PC principles, however their attitudes and indication for referral to PC revealed an association of PC with death and dying(46).

A study was done in western Kenya to determine accessibility and obstacles to PC and HCPs grasp and understanding of pain control in PC. They sampled 22 facilities and key informants included medical officers, nurses and clinical officers. Dominant themes comprised of education and training, service provision, perception of PC, and pain control. The HCPs knew PC with 18% having been formally training. About 64% were aware that morphine was on the essential drug list, 36% had formerly ordered opioids, and 23% had purposely ordered the opioids for palliation. There were concerns for opioid by

the HCPs and they included causing dependency (59%), suitable dosing (9%), side effects (9%), price (5%), and accessibility (5%)(47).

## **2.8. Theoretical Framework**

Efforts to better the application of public health and evidence-based practice hinges on behaviour change. Therefore, interventions are essential for productivity in public health and the practice of medicine. Behaviour Change Wheel (BCW) is a comprehensive framework for designing interventions.

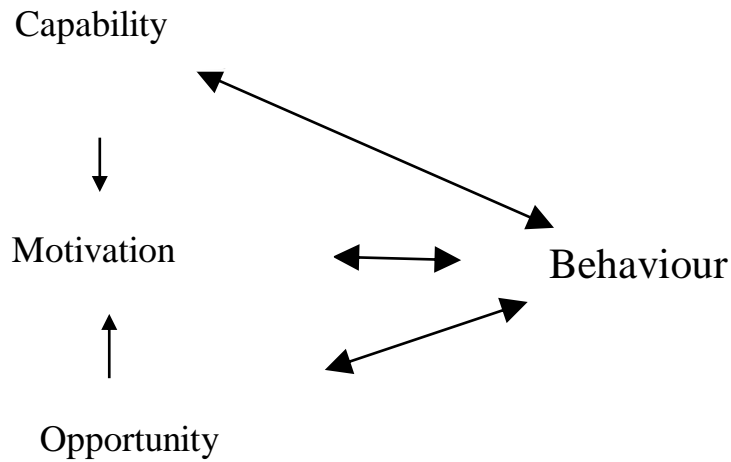
By employing the capability, opportunity, motivation and behavior (COM-B) model, it recognizes that behaviour is part of an interconnected system. The COM-B model also addresses all the domains that explain behaviour change.

Capability is described as the ability to physically and psychologically enact a behaviour. It entails possessing required knowledge and skills. Motivation is described as brain activities that activate or inhibit conduct, as well as goals and conscious decision-making. It is encompassing regular activities, emotional acknowledgement and systematic decision-making. Opportunity is described as the physical and social elements that enable or prompt behaviour.

There is possible influence between elements, for example, opportunity can affect motivation as well as capability; ratifying behaviour can change capability, opportunity, and motivation. Therefore,

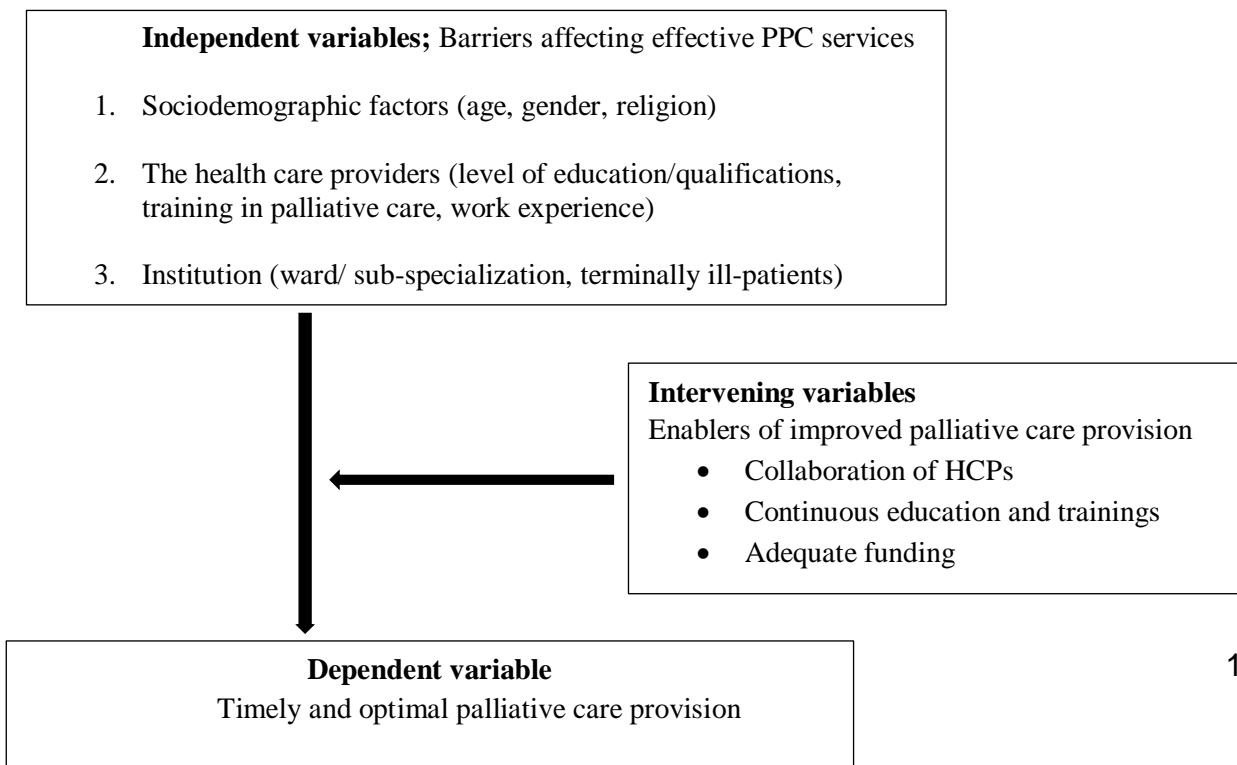
interventions should alter any of the components to set the system in a novel configuration and minimize the probability of it regressing(48,49).

**Figure 1: Capability, opportunity, motivation and behavior(COM-B) model**



## 2.9. Conceptual Framework

**figure 2: Conceptual Framework**



## **2.10. Study Justification and Utility**

Paediatric palliative care (PPC) is an emerging sector in medicine with the potential of having a positive impact on many chronically ill patients, as most PPC patients are alive for more than a year after initiating PPC. Despite various stakeholders including Kenyan government, international and local non-governmental organizations (NGOs) playing a great role in improving PC provision, the uptake has been low especially by children.

Data on PPC locally and globally are scarce. This study shall provide baseline statistics on tertiary care staffs' KAP regarding PPC, identify and explore current existing gaps in KAP to optimize PPC services at KNH. In addition, the findings of this study shall advice future policy and interventions as well as education/training programs.

## **2.11. Research Question**

What is the knowledge, attitude and practice of paediatric palliative care amongst health care practitioners at Kenyatta National Hospital and what are the barriers to service delivery?



## 2.12. Objectives

### 2.12.1. Primary Objectives

- a) To evaluate knowledge, attitude and practice (KAP) of PPC amongst health care practitioners at Kenyatta National Hospital (KNH).
  
- b) To explore barriers to PPC service delivery in KNH paediatric wards.

### 2.12.2. Secondary Objective

- a) To determine factors associated with knowledge, attitude and practice of PPC at KNH.

## **CHAPTER 3: METHODOLOGY**

### **3.1. Study Design**

A cross-sectional study that utilized both arms of qualitative and quantitative approaches (mixed-methods research) to enhance study utility. Quantitative approach was conducted by filling out a questionnaire to determine level of KAP. Through the qualitative approach, interviews were conducted with HCPs to explore factors affecting the PPC service delivery at KNH paediatric wards.

### **3.2. Study location**

The locations for the study were neonatal, paediatric medical and surgical wards (3A, 3B, 3C, 3D, NBU and 4A), paediatric specialized wards including renal, intensive care and oncology units (PRU, PICU, 1E) and the emergency and outpatient paediatric units (PEU and clinic 23) at the Kenyatta National Hospital. Annually, approximately 50,500 paediatric patients are seen at the paediatric emergency unit (PEU) and 12,200 are admitted in the newborn unit (NBU) and paediatric wards. They are managed by approximately 125 registrars and 350 nurses among other HCPs.

### **3.3. Study population**

Study respondents included nurses and residents caring for paediatric patients in the wards and the clinics at KNH.

### **Inclusion criteria**

- a) HCPs at KNH paediatric medical and surgical wards who provided written informed consent

### **Exclusion criteria**

- a) HCPs who had worked for <1 month in the paediatric wards/out-patients clinics
- b) HCPs without the messaging application “WhatsApp”

### **3.4. Sample Size Calculation**

Sample size was determined employing the Fisher’s Formulae;

$$n = \frac{z^2 p(1 - p)}{d^2}$$
$$n = \frac{(1.96)^2 0.3(1-0.3)}{(0.05)^2} + 10\% \text{ non- response}$$
$$n = 355$$

Where,

$z = 1.96$  (standard normal deviation for 95% CI (1.96))

$p = 0.3$  (expected prevalence of knowledge on palliative care (30%))

$d =$  Desired study precision usually set at 5%.

$n =$  Estimated sample size (323 + 10% non-response) **355**

The expected prevalence (p) was determined from prevalence of knowledge on palliative care at 30% by Kassa et al in Addis Ababa, Ethiopia(42).

### 3.5. Quantitative Sampling Method and Participants Recruitment Procedure

The sample size of HCPs was determined using a multistage stratified sampling technique distributed proportionately across the two cadres (residents and nurses). 261 nurses and 94 residents were selected out of the 350 nurses and 125 residents respectively. The nurses were then stratified into their respective areas; medical wards 87(33%), NBU 67(26%), specialized units 47(18%), outpatient 45(17%) and surgical ward 15(6%) nurses. The residents were also stratified proportionately into medical 83 (88%) and surgical (12%) residents. The tables below show the summary of the sampling method and sample distribution of the HCPs.

**Table 3. Sample frame**

<b>Strata</b>	<b>Population</b>	<b>Percentage (%)</b>	<b>Sample</b>
Residents	125	26%	94
Nurses	350	74%	261

**Table 4. Stratified tabulation for nurses in their respective areas**

<b>Work station</b>	<b>Percentage (%)</b>	<b>Sample</b>
Medical wards	33%	87
NBU	26%	67
Specialized units	18%	47
Outpatient	17%	45
Surgical ward	6%	15

**Table 5. Stratified tabulation for residents in their respective areas**

<b>Ward</b>	<b>Percentage (%)</b>	<b>Sample</b>
Medical	88%	83
Surgical	12%	11

### **3.6. Qualitative Sampling Method**

#### **3.6.1. Focus Group Discussions (FGDs) with HCPs**

We conducted two FGDs each with eight HCPs. This was done after HCPs have completed their ward activities and agreed to be part of the research process. They were purposely sampled so as to have a heterogeneous group comprising of HCPs with varying years of experience. The interviews were conducted on the google meet platform and confidentiality was maintained throughout the discussions.

#### **3.6.2. Key Informant Interviews (KIIs)**

The key informants were the head of department palliative care, heads of department paediatrics, KNH and University of Nairobi. The three interviews were scheduled as per their availability.

Health care practitioners(HCPs) were made aware that the survey was in no way a job performance review and all their responses remained confidential. They were invited to participate in the survey. The HCPs who accepted to participate in the survey signed an informed online-based consent form. This exercise was voluntary and free from coercion. The FGDs and KIIs were recorded and notes were taken.

### **3.7. Study Tools**

- a) Informed consent (appendix I)
- b) Pre-tested questionnaire (appendix II)
- c) Focus group discussion (FGD) topic guide (appendix III)
- d) Key informant interview (KII) topic guide (appendix IV)

### **3.8. Data Collection Procedure**

Prior to data collection commencement ethical approvals were sort from KNH and UON Ethics and Research Committee. Due to unforeseen global pandemic, we sort approval for change of data collection procedure to the online platform, this was approved. With the endorsement by the head of paediatrics department in KNH we were able to obtain names and phone numbers of eligible nurses. Eligible health care practitioners(HCPs) were enrolled into the study by receiving a link on their mobile devices to an online consent form via the messaging application WhatsApp. Upon signing the online written consent form they proceeded to complete the digital questionnaire on the “KOBO TOOL BOX”. Those respondents who chose not to participate did not proceed on to the questionnaire. A pilot study was carried out among 35 HCPs and all identified revisions were made appropriately to the questionnaire.

The data collection was carried out in two consecutive stages. First, we interviewed HCPs using the pre-tested questionnaire. We purposively called the HCPs until we reached the required number as per the framework in each department and cadre. The eligible HCPs who accepted to take part in the study signed an online-based written informed consent form. The consent form described the basis of the survey, the course of action to be followed as well as possible risks and interests of assisting in the

survey. Any pertinent concerns/questions regarding the study were answered prior to signing the consent form. This exercise was voluntary and free from coercion. The pre-tested structured questionnaire was then administered. The eligible HCPs were at liberty to fill in the questionnaire at their earliest convenience at the comforts of their homes using their own Wi-Fi or data bundles.

Secondly, FGDs and KIIs were carried out among HCPs by the principle researcher on the Google meet platform and all sessions were recorded with the consent of the respondents. Notes were taken verbatim as well. A link was sent in advance for each session.

The respondents were reminded that they can withdraw from the survey, at any stage with no risk of any repercussions.

### **The Questionnaires**

The self-administered close-ended English questionnaire was utilized for capturing data. Palliative Care Quiz For Nursing(PCQN) formed the basis for the knowledge inquiry(50). This is a validated tool that is comparable and has been utilized to assess knowledge in different cadres. Frommelt Attitude Toward Care of the Dying(FATCOD) informed the attitude inquiry(51). Practice questions were adopted from relevant literature studies(39,42).

The questionnaires were prepared in English and comprised of four sections. a) socio-demographic. b) knowledge inquiry consisted of 20 items which were answered using True (Scores 1), False (Scores 0) answers. Knowledge was termed good when respondents score  $\geq 75\%$  and poor if they score  $< 75\%$ . c) Attitude inquiry consisted of 30 items, 15 positively phrased and 15 negatively phrased inquiries and

a 5-point Likert scoring scale. Hence a maximum score of 150 and a minimum score of 30. The favorable attitude was defined as  $\geq 50\%$  while unfavorable attitude  $< 50\%$ . d) The last section consisted of 11 practical questions with multiple responses. Good practice was defined as a participants score of  $\geq 75\%$  and poor practice as  $< 75\%$ . The questionnaires were checked daily for completeness and consistency after each day of collecting data.

### **Focus Group Discussions (FDGs)**

The FDGs were carried out by the primary investigator to ensure consistency. The aim of the discussion was to explore the opinions, perceptions and experiences of the HCWs regarding PPC service delivery. Each FGD consisted of eight participants. The videos were muted to observe privacy and the microphones muted to avoid crosstalk. The investigator recorded the proceedings with consent from the participants. In addition, notes were taken verbatim.

The FDGs were conducted in four stages:

**Stage 1: Scene setting and ground rules:** the research team welcomed participants as they logged in the call. Once the group was complete, the researcher formally started the FGD by introducing herself, stating the research topic and the reason of the study. The researcher informed the participants that they are all invited to give their own opinions and that there are no correct or incorrect responses. Respondents were requested to respect each other's opinions and to allow one individual to speak at a time. The researcher requested the respondents for permission to record the discussion and assured them of confidentiality when handling the recording during data analysis.



**Stage 2: The opening topic:** The researcher engaged the participants by introducing the topic. She enquired about the participant's views and opinions on PPC.

**Stage 3: Discussion:** The participants were involved in detailed discussion of the study topic using questions provided in FDG topic guide. The researcher further explored the responses given by the participants and formulated follow-up questions.

**Stage 4: Ending the discussion:** The researcher ended the discussion by thanking the group for their participation.

### **Key Informant Interviews (KIIs)**

In depth interviews were conducted with heads of departments(HODs) from KNH palliative care unit and UON Paediatrics and Child Health department. They were scheduled according to the respondent's availability, so as not to interrupt their undertakings. The interviews were conducted on the Google meet platform and all sessions were recorded with the consent of the respondents.

### **3.9. Data Management and Analysis**

Data collected was saved in a password enabled secure server. The data was then exported to R and coded for statistical analysis. Median and interquartile ranges were used to summarize HCP knowledge, attitude and practice scores of PPC at KNH (broad objective). While multivariate logistical regression was used to determine factors associated with KAP of PPC at KNH (specific objective).

The interviews were audio recorded, transcribed, translated accordingly and cleaned for analysis. The cleaned transcript was then imported into N-Vivo version 10 for analysis. The scripts coded into emerging themes and codes. A code book was then developed from the emerging themes after validation from the supervisors. The key concepts derived from the codes was then grouped to form categories and from the various categories, themes were identified. Quotes were identified which were then used to illustrate the perception and experiences of HCPs towards PPC in KNH. This being a mixed-method study the data from the two research paradigms were then integrated.

### **3.10. Quality Assurance**

The research proposal was reviewed by the department of Paediatric and Child Health (UON) and KNH and UON Ethics and Research Committee before being allowed to carry out the study. Pre-testing involved 35 HCPs who work in the paediatric wards. The aim of the pilot test was to improve the questionnaire so that participants do not encounter difficulties while answering and facilitate unhinged data recording. It also assessed validity of the questions and reliability of the data.

Preliminary analysis of data from the pilot test was undertaken to verify that data collected answered research questions. The filled questionnaires and the audio-recordings were saved by the researcher in a password-protected file.

### **3.11. Ethical Considerations**

#### **3.11.1. Ethical Approval**

Ethical clearance was sought from KNH and UON Ethics and Research Committee. The researcher explained the basis of the survey and stressed that it was fully voluntary and that they, the respondents, have a right to withdraw from the survey at any time with no repercussions. Additionally, the researcher informed the study participants that there were no rewards/monetary gain for participating in the study.

The researcher strived to maintain trust, honesty, openness, and respect between her and the study participants. The phone number of the researcher was made available in the event that the respondents wanted clarification with regards to the study. The phone numbers and email addresses of the supervisors and the Ethics and Research Committee was also availed to the participant in case he/she had any concerns or reservations with regards to the study.

#### **3.11.2. Consent**

Informed consent was obtained from study participants after an explanation about the study was done. The consent was in simple and clear language that the study participants understood. Due to the global pandemic we were facing at the time, consent forms were sent online, where instead of the respondents appending a signature they were selecting the options YES to participate or NO to withdraw from the survey. After selecting YES to participate in the survey, they received the online questionnaire or we began either the guided focus group discussion or key informant's interview. Those who selected NO, were thanked for their time and did not receive the online questionnaire. The principal researcher frequently reviewed the respondents feedback and addressed any questions/concerns that arose.

### **3.11.3. Privacy and Confidentiality**

Privacy and confidentiality was guaranteed to the study participants as their names were omitted from the questionnaires and instead their phone numbers were used in the consent forms and questionnaires.

Questionnaires and audio recordings used for data collection were saved by the researcher in a password-protected file accessed only by the principal researcher. The supervisors were allowed access to the data on request. Furthermore, audio-recorded files, names and phone numbers were destroyed six months after completion of the study.

### **3.11.4. Study Risk**

Minimal risk was involved and the management of the patients in the wards was not interfered with throughout the study.

## **3.12. Control of Errors and Biases**

The following measures were implemented to reduce different forms of bias and errors. Questionnaire were pretested to reduce measurement bias. This ensured the questions are sensitive enough to detect the differences in the variables assessed. Selection bias was reduced by the use of the sampling frame and stratification. Information bias was reduced by assessment of the responses given to the questionnaires daily during data entry to ensure validity of collected data. All FGDs and KIIs were conducted by the principle researcher to ensure consistency and the data was then transcribed soon after to ensure accuracy.

## CHAPTER 4: RESULTS

### 4.1. Quantitative Data

#### 4.1.1. Screening and Enrollment

Of the 355 respondents screened (see figure 3), 5 declined to participate, 3 were wrong numbers, 2 had retired, 5 had no WhatsApp application on their phones, 105 did not respond and 2 had missing consent forms during analysis. Two hundred and thirty three (233) respondents submitted complete questionnaires for analysis, giving a response rate of 68.5%.

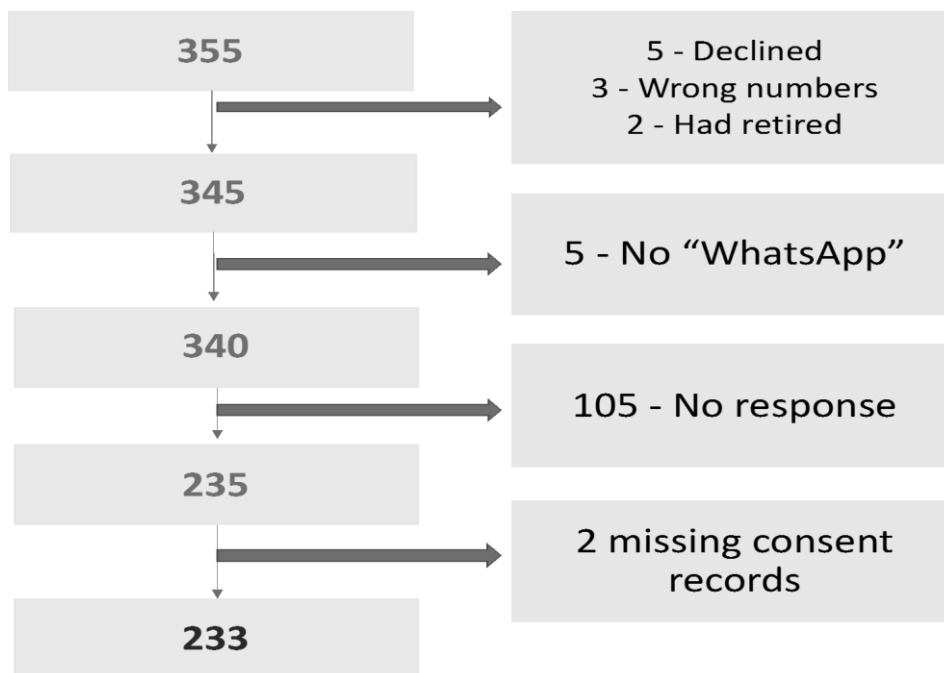


Figure 3: Screening and Enrolment

#### 4.1.2. Socio-demographic Characteristics of Participants

Majority 180 (77.3%) of the respondents were female. The median age of the participants was 34 years (interquartile range(IQR) 30-43years). Nurses were 154(66.1%) of the participants. One hundred and eighty seven(80.3%) participants had not received formal training in palliative care. The median years of practice was 9 years (IQR 6-19 years). In terms of current work station, 82(35.2%) of the respondents were from the medical wards, 66(28.3%) from the NBU, 57(24.5%) from the specialized units, 20(8.6%) were from the outpatients department and 8(3.4%) were from the surgical ward.

**Table 6: Socio-demographic Characteristics**

<b>Variable (N = 233)</b>	<b>Variable</b>	<b>Frequency</b>	<b>%</b>
<b>Age (years)</b>	20 - 30	73	31.3
	31 - 40	89	38.2
	41 - 50	45	19.3
	>50	26	11.2
	<b>Median = 34 years IQR (30 - 43 years)</b>		
<b>Gender</b>	Male	53	22.7
	Female	180	77.3
<b>Practice years</b>	<10 years	139	59.7
	11 – 20 years	52	22.3
	21 – 30 years	32	13.7
	>30 years	10	4.3
	<b>Median = 9 years IQR (6 - 19 years)</b>		
<b>Cadre</b>	Nurses	154	66.1
	Resident	79	33.9
<b>Current Working Station</b>	Medical wards	82	35.2
	NBU	66	28.3
	Outpatient	20	8.6
	Specialized units	57	24.5
	Surgical ward	8	3.4
<b>Trained in PC</b>	Yes	46	19.7
	No	187	80.3

#### **4.1.3. Knowledge of Paediatrics Palliative Care Amongst Health Care Practitioners**

Two hundred and twenty one(95%) of the respondents knew the definition of palliative care(PC) and 133(57.1%) disagreed that PC was appropriate when the patient's condition was deteriorating. Majority of the HCPs, 195(83.7%) agreed that extent of disease determines the method of pain treatment and 206(88.4%) said that adjuvant therapies are equally as important in managing pain. Similarly 177(76%) of the respondents stated that addiction was a major problem when morphine is used in long-term basis and 210(90.1%) recommended a bowel regimen for patients taking opioids. One hundred and ninety three(82.8%) of the HCPs agreed that accumulation of losses renders burnout for those working with children with palliative care needs. Of the total participants 160(68.7%) said that the philosophy of palliative care was not compatible with that of aggressive treatment while 193(82.8%) responded that chronic pain manifested differently from acute pain. From the study, of the 233 HCPs interviewed only 40(17.2%) had good knowledge in PPC (see table 7 below).

**Table 7: Health Care Practitioners Knowledge of Paediatrics Palliative Care**

<b>Variables on knowledge (N = 233)</b>	<b>Frequency (n)</b>	<b>Percentage (%)</b>
1. I know the definition of palliative care		
<b>True</b>	221	<b>94.8</b>
<b>False</b>	12	<b>5.2</b>
2. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration		
<b>True</b>	100	<b>42.9</b>
<b>False</b>	133	<b>57.1</b>
3. The extent of the disease determines the method of pain treatment		
<b>True</b>	195	<b>83.7</b>
<b>False</b>	38	<b>16.3</b>
4. Adjuvant therapies are important in managing pain		
<b>True</b>	206	<b>88.4</b>
<b>False</b>	27	<b>11.6</b>
5. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation		
<b>True</b>	117	<b>50.2</b>
<b>False</b>	116	<b>49.8</b>
6. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain		
<b>True</b>	177	<b>76.0</b>
<b>False</b>	56	<b>24.0</b>
7. Individuals who are taking opioids should also follow a bowel regime		
<b>True</b>	210	<b>90.1</b>
<b>False</b>	23	<b>9.9</b>
8. The provision of palliative care requires emotional detachment		
<b>True</b>	96	<b>41.2</b>
<b>False</b>	137	<b>58.8</b>
9. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea		
<b>True</b>	25	<b>10.7</b>
<b>False</b>	208	<b>89.3</b>
10. The philosophy of palliative care is compatible with that of aggressive treatment		
<b>True</b>	73	<b>31.3</b>
<b>False</b>	160	<b>68.7</b>
11. The use of placebos is appropriate in the treatment of some types of pain		
<b>True</b>	145	<b>62.2</b>
<b>False</b>	88	<b>37.8</b>
12. Suffering and physical pain are synonymous		
<b>True</b>	114	<b>48.9</b>
<b>False</b>	119	<b>51.1</b>



13. The accumulation of losses renders burnout inevitable for those who seek work in palliative care		
<b>True</b>	193	<b>82.8</b>
<b>False</b>	40	<b>17.2</b>
14. Manifestations of chronic pain are different from those of acute pain		
<b>True</b>	193	<b>82.8</b>
<b>False</b>	40	<b>17.2</b>
15. The pain threshold is lowered by anxiety or fatigue		
<b>True</b>	99	<b>42.5</b>
<b>False</b>	134	<b>57.5</b>
Summary index Scores: Max 15		
<b>Good knowledge 75% (<math>\geq 11</math>)</b>	<b>40</b>	<b>17.2</b>
<b>Poor knowledge &lt;75% (&lt;11)</b>	193	<b>82.8</b>

#### 4.1.4. Attitude of Paediatrics Palliative Care Amongst Health Care Practitioners

One hundred and twenty nine(55.3%) of the interviewed HCPs strongly agreed that caring for the dying person is a worthwhile experience. With regards to withdrawal of their involvement with the patient as they near death 136(58.4%) HCPs strongly disagreed and 134 (57.5%) strongly agreed that the dying person should be given honest answers about their condition. On the other hand, 153(65.7%) and 177 (75.9%) of the respondents strongly agreed that care should extend to the family of the dying person and it should continue throughout the period of grief and bereavement respectively. Over 60% of the participants strongly agreed that the family should be involved in the physical care of the dying person and aim at maintain as normal an environment as possible for their dying member. Overall, all(100%) of the respondents had favorable attitude toward PPC (see table 8).

**Table 8: Health Care Practitioners Attitude of Paediatrics Palliative Care**

	<b>Statement on Attitude (N = 233)</b>	<b>SA (%)</b>	<b>A (%)</b>	<b>U(%)</b>	<b>D (%)</b>	<b>SD (%)</b>
1.	Giving care to the dying person is a worthwhile experience	129 (55.3)	66 (28.3)	21 (9.0)	12 (5.2)	5 (2.2)
2.	Death is not the worst thing that can happen to a person	47 (20.2)	74 (31.8)	28 (12.0)	44 (18.9)	40 (17.1)
3.	I would be uncomfortable talking about impending death with the dying person	48 (20.6)	97 (41.6)	22 (9.4)	50 (21.5)	16 (6.9)
4.	Caring for the patient's family should continue throughout the period of grief and bereavement	177 (75.9)	47 (20.2)	4 (1.7)	5 (2.2)	0 (0)
5.	I would not want to care for a dying person	11 (4.7)	21 (9.0)	31 (13.3)	109 (46.7)	61 (26.3)
6.	The length of time required to give care to a dying person would frustrate me	14 (6.0)	45 (19.3)	41 (17.6)	95 (40.8)	38 (16.3)
7.	It is difficult to form a close relationship with the family of a dying person	12 (5.2)	35 (15.0)	22 (9.4)	116 (49.8)	48 (20.6)
8.	There are times when death is welcomed by the dying person	91 (39.1)	114 (48.9)	13 (5.6)	10 (4.3)	5 (2.1)
9.	When a patient asks, "Am I dying?" I think it is best to change the subject to something cheerful	28 (12.0)	58 (24.9)	27 (11.6)	76 (32.6)	44 (18.9)
10.	The family should be involved in the physical care of the dying person	148 (63.5)	77 (33.1)	2 (0.8)	2 (0.8)	4 (1.8)
11.	I would hope the person I'm caring for dies when I am not present	38 (16.3)	74 (31.8)	34 (14.6)	67 (28.8)	20 (8.5)
12.	I am afraid to become friends with a dying patient	13 (5.6)	41 (17.6)	20 (8.5)	113 (48.5)	46 (19.8)
13.	I would feel like running away when the person actually died	17 (7.3)	27 (11.6)	19 (8.2)	118 (50.6)	52 (22.3)
14.	As a patient nears death, the nurse/ doctor should withdraw his or her involvement with the patient	6 (2.6)	1 (0.4)	3 (1.3)	87 (37.3)	136 (58.4)
15.	Families should be concerned about helping their dying member make the best of his or her remaining life	166 (71.3)	64 (27.5)	1 (0.4)	1 (0.4)	1 (0.4)

16.	Families should maintain as normal an environment as possible for their dying member	144 (61.8)	75 (32.2)	5 (2.1)	5 (2.1)	4 (1.8)
17.	It is beneficial for the dying person to verbalize his or her feelings	158 (67.8)	68 (29.2)	4 (1.8)	1 (0.4)	2 (0.8)
18.	Care should extend to the family of the dying person	153 (65.7)	71 (30.5)	5 (2.1)	1 (0.4)	3 (1.3)
19.	The dying person and his or her family should be the in-charge decision makers	79 (33.9)	87 (37.3)	28 (12.0)	31 (13.3)	8 (3.5)
20.	Addiction to pain relieving medication should not be a concern when dealing with a dying person	76 (32.6)	52 (22.3)	17 (7.3)	67 (28.8)	21 (9.0)
21.	I would be uncomfortable if I entered the room of a terminally ill person and found him or her crying	42 (18.0)	79 (33.9)	26 (11.2)	68 (29.2)	18 (7.7)
22.	Dying persons should be given honest answers about their condition	134 (57.5)	71 (30.5)	16 (6.9)	9 (3.9)	3 (1.2)
23.	Educating families about death and dying is not a nurse's or doctor's responsibility	3 (1.3)	11 (4.7)	16 (6.9)	87 (37.3)	116 (49.8)
24.	Family members who stay close to a dying person often interfere with the professional's job with the patient	13 (5.5)	50 (21.5)	24 (10.3)	103 (44.2)	43 (18.5)
25.	It is possible for the nurse/ doctor to help patients prepare for death	104 (44.7)	107 (45.9)	10 (4.3)	7 (3.0)	5 (2.1)
Summary Index Scores: Max 125						
<b>Favorable attitude <math>\geq</math> 50% (<math>\geq</math> 62.5)</b>		<b>233</b>		<b>100%</b>		
<b>Unfavorable attitude &lt;50 % (&lt;62.5)</b>		<b>0</b>		<b>0</b>		

Likert Scale; SA: Strongly Agree, A: Agree, U: Uncertain, D: Disagree, SD: Strongly Disagree

#### **4.1.5. Practice of Paediatrics Palliative Care Amongst Health Care Practitioners**

One hundred and seventy five(75.1%) of the respondents initiated PPC at time of diagnosis with 207(88.8%) of them informing the terminally ill patients about their diagnosis. With regards to addressing psychological issues of the patients, 219(94%) of the participants provided counselling, while 147(63.1%) opted to give emotional support. Majority of the respondents (98.3%) perceived terminally ill patient concern/questions as their right. Regarding decision making, 179(76.8%) of the respondents involved the patients and 206(88.4%) involved the family in the decision making. The family involvement in the decision making process was a crucial conduit for communication as reported by 192(82.4 %) of the participants. It emerged that the commonly used medication for severe pain was morphine 222(95.3%), paracetamol or ibuprofen 60(25.8%) and codeine 28(12%). In general, only 97(41.6%) of the respondents exhibited good practice of PPC (see table 9).

**Table 9: Practice of Paediatrics Palliative Care Amongst Health Care Practitioners**

<b>Response to Palliative Care Practice, Multiple Choices, N= 233</b>	<b>Frequency</b>	<b>%</b>
<b>1. Initiate palliative care discussion:</b>		
During diagnosis	175	75.1
When the disease progresses	83	35.6
At the end of life	14	6.0
<b>2. Do you inform terminally ill patient about their diagnosis?</b>		
Yes	207	88.8
No	4	1.7
Depending on family's wish	41	17.6
Inapplicable	6	2.6
<b>3. Factors considered when dealing with terminally ill patient:</b>		
Spiritual	183	78.5
Medical situation	187	80.3
Cultural	145	62.2
Psychological	195	83.7
<b>4. To address spiritual issues</b>		
Connect with spiritual counselor	203	87.1
Listen with empathy	101	43.3
Impose your own view	3	1.3
Understand patient reaction	111	47.6
<b>5. Cultural assessment during patient care should include:</b>		
Truth telling and decision making	121	51.9
Preference regarding disclosure of information	121	51.9
Dietary preference	78	33.5
Language, family communication	145	62.2
Perspective on death, suffering and grieving	154	66.1
<b>6. Address psychological issues by</b>		
Emotional support	147	63.1
Counselling the patient	219	94.0
Hiding the truth	1	0.4
<b>7. Whom do you involve in decision making?</b>		
Patient	179	76.8
Family	206	88.4
My own	23	9.9
Other health professional	150	64.4
<b>8. How do you perceive terminally ill patient's concerns and questions?</b>		
Patient right	229	98.3
Threat	1	0.4
Doubting your professionalism	0	0

Attention seeking behaviour	7	<b>3.0</b>
<b>9. Communication to the family of terminally ill patient depends on:</b>		
Family's ability to assimilate	122	<b>52.4</b>
Their involvement in decision making	192	<b>82.4</b>
Your willingness to disclose information	37	<b>15.9</b>
<b>10. Commonly used medication in your practice for severe pain?</b>		
Paracetamol/Ibuprofen	60	<b>25.8</b>
Codeine	28	<b>12.0</b>
Morphine	222	<b>95.3</b>
<b>11. How do you assess patient pain?</b>		
Grade with face	155	<b>66.5</b>
Intensity	156	<b>67.0</b>
Location	77	<b>33.0</b>
Quality	77	<b>33.0</b>
Summary Index Scores; Max 41		
<b>Good Practice <math>\geq 50\%</math>(<math>\geq 21</math>)</b>	<b>97</b>	<b>41.6%</b>
<b>Poor Practice <math>&lt;50\%</math>(<math>&lt;21</math>)</b>	<b>136</b>	<b>58.4%</b>

#### **4.1.6. Socio-demographic Characteristics Associated with Knowledge of Paediatrics Palliative Care Using Multivariable Analysis**

From our multivariable analysis only gender and cadre had a significant association with the level of knowledge of PPC amongst the HCPs interviewed. Age, work experience, current working station and training in palliative care did not have significant association. Male gender were four times more likely (AOR=3.68, 95% CI 1.22-15.96; P=0.0403) of having good knowledge in PPC as compared to female gender. Likewise, residents were approximately five times likely to have good knowledge of PPC (AOR = 4.89, 95% CI 1.8-15.77; P=0.0035) when compared to the nursing officers (see table 10).

**Table 10: Socio-demographic Characteristics Associated with Knowledge of Paediatrics Palliative Care Using Multivariable Analysis**

Variables	Good (n = 40) (%)	Poor (N = 193) (%)	Crude Odds Ratio (CI)	Adjusted Odds Ratio (CI)	P - value
Age range (Yrs)					
20-30	13 (32.5)	60 (31.1)	ref		
31-40	14 (35.0)	75 (38.7)	1.11 (0.38 - 3.30)		0.853
41-50	6 (15.0)	39 (20.2)	11.61 (1.21 - 272.93)		0.055
51-60	7(17.5)	19 (9.9)	14.80 (0.92 - 489.9)		0.778
Gender*					
<b>Male</b>	<b>3 (7.5)</b>	<b>50 (26)</b>	<b>4.17 (1.23 – 20.24)</b>	<b>3.68 (1.22 – 15.96)</b>	<b>0.0403*</b>
Female	37 (92.5)	143 (74)	ref	ref	
Practice years range					
1-10	22 (55.0)	117 (60.6)	ref	ref	
11-20	6 (15.0)	46 (23.8)	0.78 (0.19 – 3.31)	2.53 (0.95 – 7.60)	0.076
21-30	8 (20.0)	24 (12.4)	0.08 (0.03 -0.93)	1.17 (0.45 -3.27)	0.749
31-40	4 (10.0)	6 (3.2)	0.04 (0.00 – 0.81)	0.59 (0.15 – 2.59)	0.464
Cadre*					
Nursing officer	35 (87.5)	119 (61.7)	ref	ref	
<b>Resident</b>	<b>5 (12.5)</b>	<b>74 (38.3)</b>	<b>6.21 (1.88 – 25.38)</b>	<b>4.89 (1.8 – 15.77)</b>	<b>0.0035*</b>
Current working station					
Medical wards	14 (35.0)	68 (35.2)	ref		
NBU	14 (35.0)	52 (26.9)	1.22 (0.46 – 3.28)		0.692
Outpatient	1 (2.5)	19 (9.9)	4.52 (0.73 – 88.46)		0.175
Specialized units	9 (22.5)	48 (24.9)	1.45 (0.50 – 4.37)		0.501
Surgical ward	2 (5.0)	6 (3.1)	0.14 (0.17 – 1.28)		0.605
Trained in PC					
Yes	10 (25.0)	36 (18.6)	0.69 (0.32 – 1.59)		0.597
No	30 (75.0)	157 (81.4)	ref		

\*Statistically significant at p <0.05

#### **4.1.7. Socio-demographic Characteristics Associated With Practice of Paediatrics Palliative Care Using Multivariable Analysis**

Only cadre had a significant association with the practice of PPC amongst the HCPs interviewed. There was no statistically significant association with gender, age, work experience, current working station and training in palliative care. Residents were 35% (AOR= 0.35, 95% CI 0.20-0.62; P=0.0003) likely to have poor practice of PPC as compared to the nursing officers (see table 11).



**Table 11: Socio-demographic Characteristics Associated With Practice of Paediatrics Palliative Care Using Multivariable Analysis**

Variables	Good (n = 97) (%)	Poor (n = 136) (%)	Crude Odds Ratio(CI)	Adjusted Odds Ratio(CI)	P-value
Age range (years)					
20-30	25 (25.8)	48 (35.3)	ref		
31-40	45 (46.4)	44 (32.4)	0.60(0.29 – 1.26)		0.176
41-50	19 (19.5)	26 (19.1)	0.61 (0.16 – 2.35)		0.474
>50	8 (8.3)	18 (13.2)	1.13 (0.18 – 7.63)		0.901
Gender					
Male	24 (24.7)	29 (21.3)	1.06 (0.54 – 2.11)		0.862
Female	73 (75.3)	107 (78.7)	ref		
Practice years range					
1-10	59 (60.8)	80 (58.8)	ref		
11-20	23 (23.7)	29 (21.3)	0.71 (0.25 – 2.03)		0.522
21-30	12 (12.4)	20 (14.7)	0.69 (0.14 -3.25)		0.634
31-40	3 (3.1)	7 (5.2)	0.71 (0.07 – 7.22)		0.770
Cadre					
Nursing officer	51 (52.6)	103 (75.7)		ref	
<b>Resident</b>	<b>46 (47.4)</b>	<b>33 (24.3)</b>	<b>0.28 (0.13 – 0.59)</b>	<b>0.35 (0.20 – 0.62)</b>	<b>0.0003*</b>
Current working station					
Medical wards	38 (39.2)	44 (32.4)			
NBU	20 (20.6)	46 (33.8)	1.46 (0.69 – 3.09)		0.327
Outpatient	10 (10.3)	10 (7.4)	0.58 (0.19 – 1.67)		0.310
Specialized units	25 (25.8)	32 (23.5)	0.93 (0.44 – 1.97)		0.843
Surgical ward	4 (4.1)	4 (2.9)	1.50 (0.31 – 7.36)		0.608
Trained in PC					
Yes	18 (18.6)	28 (20.6)	1.08 (0.53 – 2.20)		0.701
No	79 (81.4)	108 (79.4)	ref		

\*Statistically significant at p <0.05

## 4.2. Qualitative Data

### 4.2.1. Knowledge of Paediatric Palliative Care

From both focus group discussions (FGDs) and key informants interviews (KIIs), there was emphasis that paediatric palliative care (PPC) requires a multi-disciplinary kind of approach. The patient and their family require emotional, spiritual, social, psychological and physical support apart from alleviating pain and other symptoms. This care is holistic and does not end at death but goes beyond, through the loss and bereavement.

*“ ... it should be multi-disciplinary; involve the doctors, involve the nurse, involve the patient.” FGD1*

*“So, I believe it can only happen when it is multi-disciplinary because the physician has to be there, the nurse has to be there, maybe the family members, if there are spiritual people, you may also need some spiritual guidance.” FGD2*

*“... the care we give to those patients or those children who have end stage diseases or chronic diseases or who are terminally ill. So, we try to improve their quality of life and we try also to offer supportive management and long-life treatment for those with chronic diseases...and also support to their relatives.” FGD1*

In terms of initiation and uptake of PPC most respondents agreed that PPC should be initiated at the time of diagnosis however in reality this is not what happens. Most of PPC is initiated when it's too late and the condition has progressed. Uptake of PPC services is very scanty except for cancer and HIV positive patients and this could be attributed to lack of proper understanding of PPC and reliance on referrals.

*“Yea, I think at the time of diagnosis but it’s also a continuous process because I think as clinicians as much as we introduce palliative care at the time of diagnosis, we usually don’t like take it that seriously so you just mention it but you will not follow up on the process. So, I think as much as we are introducing it at the time of diagnosis, we need to continue with it, yea it’s not just diagnosis and starting it and leaving it there, it is something that we need to follow up.” FGD1*

*“my understanding of it not just at the end, it is the whole spectrum so you would have uptake for some conditions such as sickle cell there would be fairly good pain management but apart from that other conditions, I think it is patchy, other conditions it is patchy., if it is not cancer, it is not HIV, anyone else who might need palliation with other condition might not feel it as much. I don’t think we are set up to pay attention to that as much. So, this it is high in certain dockets but it is not universally high.”*

*KII2*

#### **4.2.2. Barriers to Paediatric Palliative Care Service Delivery**

The main themes identified from the focus group discussions(FGDs) and key informants interviews(KIIs) were;

Theme 1: Deficient knowledge

Theme 2: Staff shortage

Theme 3: Bureaucracy

Theme 4: Reliance on referrals

Theme 5: Late referrals

Theme 6: Stigma

## **Theme 1: Deficient Knowledge**

Majority of the participants noted that they had not been formally trained in PPC and thus had deficient knowledge pertaining the scope of PPC. They further stated that, they only considered PPC when dealing with cancer patients only and in other disease processes only when the patient deteriorates.

*“It comes up in some topic we were doing. Topics like pain...But not actually as a different unit or a different entity that is taught in undergraduate.”* FGD1

*“... a number of people their understanding is that palliation should take, should start when everything else has failed.”* KII2

*“now one challenge among the health care providers sometimes is the lack of knowledge on the scope of palliative care because sometimes they call out any patient who is diagnosed with cancer, we will be called to counsel the patient.”* KII1

## **Theme 2: Staff Shortage**

Many of the respondents stated that the existing staff shortage was a major hinderance to provision of PPC services. The shortage was directly linked to increased daily workload which resulted in fatigue hence negatively affecting PPC. Also, the number of trained providers with respect to the demand was not comparable as KNH is a public tertiary facility with vast number of patients; many of whom are candidates of PPC services.

*“We have a challenge of the patients requiring palliative care vis a vis the capacity that is there.”* FGD2

*“... not just in Kenya, but worldwide there is a big need for trained palliative care health providers...”*

KII1

*“One of them already said is workload I think the workload is so much. So, you want to do other things and still we said palliative care actually you need a lot of time. So, the workload is quite much.”* FGD2

*“Obviously being a public institution, we have shortages of staff, people are over whelmed and so on.”*

KII2

### **Theme 3: Bureaucracy**

Bureaucracy was mentioned as a barrier to PPC service delivery as it led to unnecessary delays in instituting definitive management even in emergencies. It also hindered total care approach that involves and includes the family in the care of their loved one.

*“You know like cancer patient there are some emergencies, ...it’s not a must we have to wait for a palliative nurse to counsel a patient before starting treatment”.* FGD1

*“The set-up is very challenging, the infrastructure in Kenyatta doesn’t allow family to be present when the child is being cared for.”* KII2

### **Theme 4: Reliance on Referrals**

Palliative care unit is relatively new and they do not have a ward per se and thus depend solely on referrals from the residents and nurses. This has been a major challenge for the team as it directly undermines their effectiveness, efficiency and uptake of PPC.

*“so, there are some children who need palliative care who have not been referred to the unit so they end up not being seen or not receiving the services...” KII1*

### **Theme 5: Late Referrals**

The participants noted that they turn to PPC when their patients conditions are deteriorating. These late referrals are contrary to PPC services but in-line with end of life care.

*“...and sometimes the referrals are late. They send the children when they are too sick so when we come in, even the service we are offering ends up being end of life care alone instead of palliative care.” KIII*

*“most of the time palliative care is usually introduced when you now realize, oh, this thing is actually terminal. Like you are not going to cure it, you know, or treat it until the patient is well. That’s usually the time most people think about palliation.” FGD1*

### **Theme 6: Stigma**

From the discussions we identified stigma as a barrier to PPC service delivery. It was more among parents/ guardians as they associated PPC with loss and majority were lost to follow-up upon discharge from the wards. The participants felt that there was need to change the narrative and assure the parents/guardians that PPC can be given concurrently with curative care.

*“...something that we need to address. Some parents will refuse to come to the unit if they have been discharged through the unit. Patients need to understand that palliative care can be given alongside curative care and it doesn’t mean that anyone receiving palliative care is going to die” KII01*

## CHAPTER 5: DISCUSSION

Paediatrics palliative care(PPC) is essential in the management of children with life-limiting and life-threatening conditions. This study sought to evaluate health care practitioners(HCPs) knowledge, attitude and practice(KAP), as well as explore barriers to PPC service delivery in a tertiary public facility, Kenyatta National Hospital(KNH). It was necessary to first establish a baseline KAP in our region so that relevant educational programs could be designed in future.

The study results showed that the majority(83%) of the HCPs had poor knowledge, with knowledge score of 17.2% . The results were similar to studies done in Palestine(20.8%) and Iran(19%)(34,39), and contrary to those in Thailand where knowledge level was 55.7%(52). The poor knowledge scores could be attributed to the fact that majority(80%) of the respondents had not received any formal training in palliative care. Findings that were consistent to those from Western Kenya, Ethiopia and India (42,47,53). In spite of this, majority(95%) of the respondents knew the definition of PPC and were able to list patients who should be enrolled for PPC services. There was significant association between gender(male) and cadre(residents) with the level of knowledge on PPC. Others studies in Ethiopia, Lebanon and Palestine, showed that work experience, training in PPC and ward allocation had strong influence on the level of PPC knowledge(42)(38)(34).

All of our participants had favorable attitude towards PPC, which is in-keeping with findings in Ethiopia(76%) and India(93%)(42,54). The reason for this could be that the respondents had a better understanding of the FATCOD scale. Almost two thirds(62%)of the respondents were uncomfortable talking about death with a dying patient, a finding that was higher than that from Ethiopia(36.5%) and

Egypt (43.7%)(42,55). From the study 37% of the participants responded that its best to change the subject to a cheerful one when asked by a patient, “Am I dying?”. Lower than the findings from Ethiopia(50%) and higher than that from Egypt(20%)(42,55). It’s evident that, despite our respondents having favorable attitude towards PPC, they were grappling with discussions surrounding death. This could be emanating from the feeling of deficiency in terms of knowledge and staff shortage that rendered them unsure on how to proceed in such instances, similar to survey done by Oakley(40).

In this study, 41.6% of the respondents had good practice which was higher than in Iran(6%) and Lebanon(23%) while lower than in America(88.5%)(37,39,56). Our findings could be related to the respondents poor knowledge towards PPC and late referrals, which replaced PPC services with end-of-life care. Majority(89%) of the participants inform terminally ill patients about their diagnosis. This finding was higher compared to similar studies done in Lebanon(19%)(37)and lower than in Norway(100%)(57). It was evident that psychological(83.7%) and medical situation(80.3%) were the predominant factors considered when dealing with terminally ill patients. This was in contradiction to the studies in Ethiopia and Lebanon, where spiritual and cultural factors predominated(42)(37). Our findings could be as a result of our spiritual and cultural diversity.

Appropriate pain management in children is considered a human right. Nighty five percent of the respondents reported using morphine to treat severe pain. Contrary to studies done in Western Kenya, where morphine was rarely prescribed due fear of addiction and unavailability/erratic supplies of opioid analgesics(47).



Stigma was uncovered to be a major hinderance to PPC service delivery primarily among parents/guardians to paediatric patients referred for palliative care. Enrolment to care was synonymous to death/dying, similar to studies done in Switzerland and United Kingdom(44,46). In order to overcome stigma, all stakeholders need to be involved and assure parents/guardians that curative care and PPC can be provided concurrently.

### **5.1. Study Strengths**

Use of validated tools to assess knowledge and attitude. Multi-disciplinary collaboration, the participants were from the paediatric medical and surgical departments. The study aimed to assess KAP in PPC and factors hindering service delivery in tertiary public facility with a functional palliative care unit.

### **5.2. Study Limitations**

The drawbacks included, lack of a validated tool to assess practice. However, the questions utilized were comparable to previous studies. The study was limited to HCPs working in a tertiary public facility and the findings may not be generalized to the primary, secondary and private facilities in Kenya.

### **5.3. Conclusion**

Majority of the HCPs had not received formal training in PPC and this was evident from the poor knowledge and practice scores. All the respondents had favorable attitude and their involvement with

children with life-limiting and life-threatening conditions could have a tremendous positive impact in this novice specialty of medicine.

PPC services are among the many services offered at KNH. It was a milestone achieved when the palliative care unit was set up, unfortunately, uptake has been undermined by deficient knowledge amongst the HCPs, stigma, bureaucracy, poor and late referral processes and staff shortages.

#### **5.4. Recommendations**

The recommendations are for the different cadres, i.e. the residents and nursing teams and both genders to work together to ensure paediatrics palliative care services are initiated in a timely fashion and appropriately. We recommend on job continuous medical educations and trainings to bridge the gap of poor practice and deficient knowledge as well as demystifying the stigma surrounding palliative care. To expand the human resource as well as streamline referral processes and workplace bureaucracy.

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# **APPENDICES**

## **Appendix I: Health care provider consent form**

### **Title of Study**

**KNOWLEDGE, ATTITUDE, PRACTICE AND BARRIERS TO SERVICE  
DELIVERY OF PAEDIATRIC PALLIATIVE CARE AMONGST HEALTH CARE  
PRACTITIONERS AT KENYATTA NATIONAL HOSPITAL.**

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### **Introduction**

I would like to tell you about a study that I am conducting. My name is Wangui Mavumba and I am a post graduate student undertaking a degree in Master of Medicine in Paediatric and Child Health at the University of Nairobi. This study is on paediatric palliative care amongst health care practitioners at Kenyatta National Hospital and is part of the requirement to be

fulfilled for the award of the degree. 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. \_\_\_\_\_

### **Purpose of the study**

The purpose of this study is to determine the knowledge, attitude and practice of paediatric palliative care amongst health care practitioners at Kenyatta National Hospital and explore barriers to service delivery. Participants in this research study will be assessed on the level of knowledge, attitude and practice of palliative care, factors that affect level of knowledge, attitude and practice and factors that hinder service delivery will be explored.

I will be interviewing health care practitioners caring for paediatric patients. There will be approximately three hundred and fifty five participants in this study. I am asking for your consent to consider participating in this study. If you agree to participate in this study, the



following things will happen: I will be interview you in a private area where you feel comfortable answering questions. The interview will last approximately twenty minutes.

### **Benefits**

Your participation in this study will help us identify the factors that affect level of knowledge, attitude and practice of palliative care and identify the barriers to optimum service delivery with an aim of improving care to children with palliative needs.

### **Voluntariness of participation**

This study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point. Refusal to participate will not compromise your job in any way.

### **Confidentiality**

The information obtained will be kept in strict confidence. No specific information will be released to any person without your written permission. We will discuss general overall findings regarding all care practitioners but nothing specific will be discussed regarding you. We will also not reveal your identity in these discussions.

### **Problems or Questions**

If you have further questions or concerns about participating in this study, please call or send a text message to the researcher on 0725351061 or the research supervisors Dr. Marangu on 0721282815, Dr. Kariuki on 0722679119. 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.

### **Risks**

Medical research has the potential to introduce psychological, social, emotional and physical 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. There is no monetary reward for agreeing to participate in the study.

## **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 counsellor. 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**

**Participant printed name:** \_\_\_\_\_

**Participant signature** \_\_\_\_\_ **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** \_\_\_\_\_

## Appendix II: Questionnaire

### KNOWLEDGE, ATTITUDE, PRACTICE AND BARRIERS TO SERVICE DELIVERY OF PAEDIATRIC PALLIATIVE CARE AMONGST HEALTH CARE PRACTITIONERS AT KENYATTA NATIONAL HOSPITAL

Questionnaire No. \_\_\_\_\_ Initials \_\_\_\_\_ Date \_\_\_\_\_

#### Instructions

Please Circle the letter with the appropriate answer where appropriate

#### Section A: Care providers' socio-demographic characteristics

1. Age \_\_\_\_\_ years
  
2. Gender
  - a) Male
  - b) Female
  
3. Cadre
  - a) Registrar
  - b) Nursing Officer
  
4. Number of years in medical practice \_\_\_\_\_
  
5. Currently serving in

a)	Medical wards
b)	NBU
c)	Specialized units
d)	Outpatient
e)	Surgical ward

6. Received training in palliative care?

- a) Yes
- b) No

**Section B: Please Circle the letter with the appropriate answer where, T = true, F = false**

1) Do you know the definition palliative care?

T = true, F = false

2) Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration

T = true, F = false

3) The extent of the disease determines the method of pain treatment

T = true, F = false

4) Adjuvant therapies are important in managing pain

T = true, F = false

5) It is crucial for family members to remain at the bedside until death occurs

T = true, F = false

6) During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation

T = true, F = false

7) Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain

T = true, F = false

8) Individuals who are taking opioids should also follow a bowel regime

T = true, F = false

9) The provision of palliative care requires emotional detachment

T = true, F = false

10) During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea

T = true, F = false

11) Men generally reconcile their grief more quickly than women

T = true, F = false

12) The philosophy of palliative care is compatible with that of aggressive treatment

T = true, F = false

13) The use of placebos is appropriate in the treatment of some types of pain

T = true, F = false

14) In high doses, codeine causes more nausea and vomiting than morphine

T = true, F = false

15) Suffering and physical pain are synonymous

T = true, F = false

16) Meperidine (Demerol) is not an effective analgesic in the control of chronic pain

T = true, F = false

17) The accumulation of losses renders burnout inevitable for those who seek work in palliative care

T = true, F = false

18) Manifestations of chronic pain are different from those of acute pain

T = true, F = false

19) The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate

T = true, F = false

20) The pain threshold is lowered by anxiety or fatigue

T = true, F = false

**Section C: Please Circle the letter with the appropriate answer where**

**SD- Strongly Disagree; D- Disagree; U- Uncertain; A- Agree; SA- Strongly Agree**

1. Giving care to the dying person is a worthwhile experience. SD D U A SA
2. Death is not the worst thing that can happen to a person. SD D U A SA
3. I would be uncomfortable talking about impending death with the dying person. SD D U A SA
4. Caring for the patient's family should continue throughout the period of grief and bereavement. SD D U A SA
5. I would not want to care for a dying person. SD D U A SA

6. The non-family caregivers should not be the one to talk about death with the dying person. SD D U A SA
7. The length of time required to give care to a dying person would frustrate me. SD D U A SA
8. I would be upset when the dying person I was caring for gave up hope of getting better. SD D U A SA
9. It is difficult to form a close relationship with the family of a dying person. SD D U A SA
10. There are times when death is welcomed by the dying person. SD D U A SA
11. When a patient asks, "Am I dying?" I think it is best to change the subject to something cheerful. SD D U A SA
12. The family should be involved in the physical care of the dying person. SD D U A SA
13. I would hope the person I'm caring for dies when I am not present. SD D U A SA
14. I am afraid to become friends with a dying patient. SD D U A SA
15. I would feel like running away when the person actually died. SD D U A SA
16. Families need emotional support to accept the behavior changes of the dying person. SD D U A SA
17. As a patient nears death, the non-family caregiver should withdraw from his or her involvement with the patient. SD D U A SA
18. Families should be concerned about helping their dying member make the best of his or her remaining life. SD D U A SA
19. The dying person should not be allowed to make decisions about his or her physical care. SD D U A SA
20. Families should maintain as normal an environment as possible for their dying member. SD D U A SA
21. It is beneficial for the dying person to verbalize his or her feelings. SD D U A SA
22. Care should extend to the family of the dying person. SD D U A SA
23. Caregivers should permit dying persons to have flexible visiting schedules. SD D U A SA
24. The dying person and his or her family should be the in-charge decision makers. SD D U A SA



25. Addiction to pain relieving medication should not be a concern when dealing with a dying person. SD D U A SA
26. I would be uncomfortable if I entered the room of a terminally ill person and found him or her crying. SD D U A SA
27. Dying persons should be given honest answers about their condition. SD D U A SA
28. Educating families about death and dying is not a non-family caregiver's responsibility. SD D U A SA
29. Family members who stay close to a dying person often interfere with the professional's job with the patient. SD D U A SA
30. It is possible for non-family caregivers to help patients prepare for death. SD D U A SA

**Section D: Please Circle the letter with the appropriate answer/s**

1. Initiate palliative care discussion:
- a) During diagnosis
  - b) When the disease progress
  - c) At the end of life
2. Do you inform terminally ill patient about their diagnosis?
- a) Yes
  - b) No
  - c) Depending on family's wish
  - d) Inapplicable
3. Factors considered when dealing with terminally ill patient:
- a) Spiritual
  - b) Medical situation
  - c) Cultural
  - d) Psychological
4. Address spiritual issue:

- a) Connect with spiritual counselor
- b) Listen with empathy
- c) Impose your own view
- d) Understand patient reaction

5. Cultural assessment during patient care should include:

- a) Truth telling and decision making
- b) Preference regarding disclosure of information
- c) Dietary preference
- d) Language, family communication
- e) Perspective on death, suffering & grieving

6. Addressing psychological:

- a) Emotional support
- b) Counseling the patient
- c) Hiding the truth

7. Whom do you involve in decision making?

- a) Patient
- b) Family
- c) My own
- d) Other health professional

8. How do you perceived terminally ill patient concern or question?

- a) Patient right
- b) Treat
- c) Doubting your professionalism
- d) Attention seeking behavior

9. Communication to the family of terminally ill patient depends on:

- a) Family's ability to assimilate
- b) Their involvement in decision making
- c) Your willingness to disclose information

10. Commonly use medication in your practice for severe pain?

- a) Paracetamol/Ibuprofen
- b) Codeine
- c) Morphine

11. How do you assess patient pain?

- a) Grade with face
- b) Intensity
- c) Location
- d) Quality

## **Appendix III: Focus Group Discussion Topic Guide for Health Care Providers**

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate in this group as your point of view is important to us.

### **Introduction**

The aim of this discussion will be to explore your experiences, opinions and perception of paediatric palliative care so as to identify the barriers and gaps to effective service delivery of PPC. The information from this study will be used to provide information to Ministry of Health and other stake holders in order to improve PPC practices, utilizations of available services and plan future trainings. The FDG will take about an hour.

### **Anonymity**

Despite being voice recorded, I would like to assure you that the discussion will be anonymous. The voice records will be kept safely in a locked facility and they are transcribed word for word, then they will be destroyed. The notes taken during the FGD will not record individuals' names. Try to answer and comment accurately and truthfully as possible. Kindly 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 much as possible.

### **Ground rules**

Only one person speaks at a time. If someone is talking please wait until they have finished before you start.

There are no wrong or write answers.

You do not have to speak in any particular order.

When you do have something to say, please do so, regardless of the other group members' opinions.

You do not have to agree with the views of other people in the group.

Does anyone have any questions? (Answers).

Okay let's begin

## **Questions**

1. How long have you worked as a doctor/nurse?
2. What is your understanding of paediatric palliative care (PPC).
3. Where do we get information on PPC?
4. Which patients would be enrolled to PPC?
5. What is your experience dealing with terminally ill children?
6. Does your religion influence your PPC service delivery?
7. What are your thoughts on PPC services at KNH?
8. Which factors affect how you deliver PPC services at KNH?
9. What do you think can be done in order to improve PPC services in KNH?
10. Any other comments or additional concerns?

## **Conclusion**

Thank you for participating. This has been a very informative discussion. Your opinions are a valuable asset to this study. We hope the discussion was interesting. I would like to remind any comments featured in this report will be anonymous.

## **Appendix IV: Key Informant Interview Guide**

Initial..... Age ..... Gender..... Date.....

My name is Wangui Mavumba. I am a graduate student at Nairobi University. As a requirement for partial fulfilment of a Masters in Paediatric and Child Health, I am Assessing Knowledge, Attitude and Practice of Paediatric palliative care among HCPs at KNH. The aim of this study is to explore your experiences, opinions and perceptions of PPC so as to establish factors that enhance or act as barriers to optimum service delivery.

The research is purely for academic purposes and the responses provided will be treated with utmost confidentiality. The findings will be fundamental in identifying existing gaps and help plan future training of health care practitioners in PPC .

I am requesting for your permission to record this interview. This will help me remember everything accurately and avoid unnecessary mistakes during data analysis and presentation. Therefore, please just relax and if you are uncomfortable with any question treat it as optional and do not answer it. If need be, I shall arrange to give you a copy of my research once it is completed.

Thank you for your time.

### **Questions**

1. How long have you been working in your current position or department?
2. What are the policies that have been put in place to ensure optimal palliative care services are offered to children?
3. What palliative care services are available for children at KNH?
4. What is the current uptake of PC services at KNH?
5. What can be done to improve utilization of PC services?
6. What are the challenges you face when it comes to PPC service?
7. Are there any opportunities for HCPs to have training or continuing education in PC?
8. What are the resources/partner(s) available to support above programs?
9. Any other comments or additional concerns?

Thank you very much for your valuable time. Hope you will be willing to co-operate with me should need arise.

## Appendix V: Study Timeline

Number	Activity	Estimated Time
1	Proposal development and presentation	Sept to Dec 2019
2	Submission of proposal for ethical approval	January 2020
3	Ethical corrections, pretesting and seeking permission	March to June 2020
4	Data collection	June to August 2020
5	Data analysis	September 2020
6	Thesis writing	October 2020
7	Thesis submission	December 2020

## Appendix VI: Study Budget

Category	Remarks	Units	Unit Cost (KShs)	Total (KShs)
Proposal Development	Printing drafts	500 pages	5	2,500
	Proposal Copies	10 copies	350	3,500
Data Collection	Stationery Packs (Pens and Paper)	20	100	2,000
	Research assistants	2	10,000	20,000
	Printing questionnaires	400	10	40,000
Data Analysis	Statistician	1		30,000
Thesis Write Up	Computer Services			5,000
	Printing drafts	1000 pages	5	5,000
	Printing Thesis	10 copies	500	5,000
Contingency funds				20,000
<b>Total</b>				<b>103,000</b>