KNOWLEDGE AND PRACTICES OF HEALTHCARE WORKERS ON EARLY SIGNS AND SYMPTOMS OF CHILDHOOD CANCERS IN LEVELS THREE AND FOUR PUBLIC HEALTH FACILITIES IN NAIROBI COUNTY

BY

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DECLARATION

I certify that this proposal is my original work and has not been presented for the award of a degree in any other university.

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ABBREVIATIONS

AIDS	Acquired Immunodeficiency syndrome
ALL	Acute Lymphoblastic Lymphoma
AML	Acute Myeloid Leukemia
EBV	Ebstein Barr Virus
ERC	Ethics and Research Committee
CNS	Central Nervous System
CO	Clinical Officer
COVID 19	Coronavirus disease 2019
GLOBOCAN	Global Cancer Incidence Mortality and Prevalence Number
FNA	Fine Needle Aspirate
HBV	Hepatitis B Virus
HCWs	Healthcare Workers
HICs	High Income Countries
HIV	Human Immunodeficiency Virus
HL	Hodgkin's Lymphoma
ICCC	International Classification of Childhood Cancer
KAP	Knowledge Attitude and Practice
KII	Key Informant Interview
KMPDC	Kenya Medical Practitioners and Dentists Council

KNH	Kenyatta National Hospital
LMICs	Lower- and Middle-Income Countries
MLKH	Mama Lucy Kibaki Hospital
MO	Medical Officer
MoH	Ministry of Health
NCDs	Non-Communicable Diseases
NHL	Non-Hodgkin's lymphoma
NO	Nursing Officer
PHC	Primary Health Care
RB1	Retinoblastoma 1
SDGs	Sustainable Development Goals
UoN	University of Nairobi
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Knowledge: Information and understanding of clinical features of childhood cancers.

Practice: The use of knowledge of common clinical features of common childhood cancers to manage affected children.

Child: Any persons under the age of 19 years as per WHO.

Healthcare Workers: In this study refers to paediatricians, physicians, medical officers, clinical officers and nurses.

Childhood cancers: Cancers occurring in children below 19 years of age.

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ABSTRACT

Background: By 2020 about 90% of childhood malignancy mortalities occurred in low and middle-income countries. Various childhood cancers have been found to be curable if detected early and appropriate management instituted early. However, about 80% of cases reported in Kenya are diagnosed at an advanced stage when little can be done for cure. Late diagnosis, along with shortage and uneven distribution of cancer detection and treatment facilities, staff, and equipment, lead to a high mortality rate. The level of knowledge and management practices of healthcare workers(HCWs) has an impact on early diagnosis, management and outcome of childhood malignancy.

Primary Objective: To determine the level of knowledge and to describe management practices of HCWs in level three and four facilities in Nairobi County on early signs and symptoms of childhood cancers.

Methods: This was a cross-sectional, descriptive, mixed method study on HCWs. Structured questionnaires and key informant interviews(KIIs) were used to collect data. The sample size was 128 HCWs. Medical officers(MOs), clinical officers(COs), and nurses in the paediatric, maternity, outpatient and administrative departments and paediatricians and in-charges of the selected facilities who gave informed consent were included in the study while those who had worked <3 months, interns and students were excluded.

Analysis: At the univariate stage, sociodemographic characteristics are presented as frequencies and percentages for categorical variables. Continuous variables are described using medians and IQR if skewed and with means and standard deviations if normally distributed. Regression analysis was done at the multivariate level to determine any statistically significant associations. Statistical significance was set at $p < 0.05$. For qualitative data, broad ideas, concepts or phrases were coded. Deductive and inductive approaches to content analysis were used to arrive at the themes. Data presentation was done using quotes based on the themes and concepts that emerged.

Results: ***Quantitative*****:** 128 HCWs participated in the study. 60.9% were <34 years, 69.5% were females and 60.2% were nurses. Majority of the participants scored less than 50% which was a poor score, and an indicator of poor knowledge on signs and symptoms of childhood cancer.

Unexplained weight loss was the most identifiable sign while nystagmus and diplopia were the least recognizable signs. Only 25% of the HCWs interviewed had ever participated in the management of a child with cancer; with 60.3% involved in referring suspected cases.

Qualitative: From KIIs the challenges identified in suspecting and diagnosing childhood cancer were: lack of cancer screening/diagnostic services**,** lack of training for HCWs and delayed presentation.

Conclusions: There was generally poor level of knowledge on childhood cancer among the HCWs though the knowledge on signs and symptoms among the MOs was satisfactory and inadequate among other cadres. A minority of HCWs had participated in the management of childhood cancers. There was significant association between the level of knowledge and cadre and level of knowledge and facility level. Challenges in suspecting, screening and diagnosis of childhood cancer include lack of training, screening and diagnostic services and delayed presentation.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

Cancer is a group of conditions distinguished by unchecked proliferation and dissemination of aberrant cells arising from failure of the mechanisms that regulate normal cell growth and death, causing uncontrollable cell proliferation, degradation of surrounding tissues and dissemination of the disease to other parts of the body (1). While adult cancers are mostly carcinomas involving epithelial tissues, childhood cancers mostly stem from embryonic tissues (2).

Approximately 90 per cent of paediatric cancer mortalities currently occur in low and middle-income countries(LMICs), however paediatric malignancies' link to child death in these countries has avoided public interest (3). As less children succumb to infant and childhood infectious diseases, and countries undergo demographical and epidemiologic changes, the importance of morbidity and mortality from childhood cancer and other non-communicable diseases (NCDs) will increase (3).

Among children 5 to 14 years of age, childhood malignancy is one of the leading ten causes of death in LMICs and the leading five causes of death in middle-income countries (MICs) (3). An estimated 40,000 novel cases of cancer and 28,000 mortalities from the same occur in Kenya each year, making cancer the third leading cause of mortality and representing 7 percent of all annual deaths in the country (4).

1.2 BURDEN AND EPIDEMIOLOGY OF CHILDHOOD CANCER

Childhood malignancy (defined here as cancer in children 0-19 years of age) is a top cause of mortality for children and adolescents globally (4). Each year about 300,000 children 0-19 years are diagnosed with cancer. Global Cancer Incidence, Mortality and Prevalence Number (GLOBOCAN) reported that 3,272 novel cases of childhood cancer were diagnosed in Kenya in 2018. Of these, leukaemia was leading at 16.5%, followed by Non-Hodgkin’s Lymphoma (NHL) at 14.9% (4).

In 1996, Macharia found that lymphoma (51.3%), leukaemia (21.3%), nephroblastoma (8.5%) and rhabdomyosarcoma (5.2%) are the most common paediatric cancers at the Kenyatta National Hospital (KNH) (5).

Another study done by Mwanda in several hospitals in Kenya including KNH showed that the commonest childhood tumour among children aged <16 years is Burkitt's lymphoma with the commonest solid tumour being nephroblastoma (6).

Rates of childhood malignancy incidence and mortality differ globally. In children 0-14 years of age, incidence rates vary from <100 per million-person years in parts of sub-Saharan Africa and India to >150 per million-person years in some subpopulations of North America and Europe (7). LMICs, account for 84% of childhood malignancies (8). The cure rate of paediatric cancer in high in- come countries (HICs) is >80%, compared to <10% in LMICs (4).

In the LMICs because of the higher percentage of children aged 0-14 years, the number of malignancies in this age set as a fraction of the overall number of cases in the populace is more than in the more developed countries, despite more incidences of malignancy in this age group in the more developed countries (8).

In comparison to incidence, cancer mortality in children in less developed countries is significantly higher than in more developed ones. One illustration is in 2008, when mortality was 69 per million children in Africa, in comparison to 31 per million children in Europe (8). Late presentation coupled with lags in the diagnosis of malignancy in the health care system led to the significant differences in deaths due to cancer among HICs and LMICs (9).

1.3 CLASSIFICATION OF CHILDHOOD CANCER

Childhood malignancies are categorized by the International Classification of Childhood Cancer (ICCC) as set forth by the World Health Organization (WHO) (10). While adult malignancies are classified according to the principal tumour location, this system bases malignancy classification on the histological traits of the tumour. According to the ICCC, childhood cancers are classified into 12 categories as follows (10);

I. Leukaemias, myeloproliferative and myelodysplastic diseases

II. Lymphomas and reticuloendothelial neoplasms

III. CNS and miscellaneous intracranial and intraspinal neoplasms

IV. Neuroblastoma and other peripheral nervous cell tumors

V. Retinoblastoma

VI. Renal tumors

VII. Hepatic tumors

VIII. Malignant bone tumors

IX. Soft tissue and other extraosseous sarcomas

X. Germ cell tumours, trophoblastic tumours and neoplasms of gonads.

XI. Other malignant epithelial neoplasms and malignant melanomas

XII. Other and unspecified malignant neoplasms

Cancer can also be broadly categorisedinto haematological and non-haematological malignancies. Hematological malignancies include leukaemias (acute and chronic), lymphomas (Hodgkin's and NHL), myelodysplastic syndrome among others while non-haematological malignancies include cancers of different organs e.g., kidney, bone, muscles, adrenal glands, gonads etc. (11).

1.4 RISK FACTORS FOR CHILDHOOD CANCER CAUSATION

The sources of malignancy in children are not well known. Although it's believed that various forms of cancer have different risk factors, the causative factors of most childhood malignancies are not known (12).

According to the National Cancer Institute, up to 10 per cent of all childhood malignancies are caused by a heritable mutation (12). The Retinoblastoma1 (RB1) gene mutation found in about 45% of retinoblastoma cases is an example. Inherited mutations associated with certain familial syndromes, e.g., Li-Fraumeni syndrome, among others, also raise the risk of childhood cancer (12). Similar to adults, most cancers in children are believed to arise as a result of gene mutations leading to unchecked growth of cells and ultimately cancer.

Unlike in adults though, it's been difficult to establish environmental sources of childhood cancer. In fact, most childhood malignancies are not currently thought to be caused by environmental exposures (12). Nonetheless, as per the American President's Cancer Panel, "the true burden of environmentally induced cancer has been grossly underestimated." This board reasoned that the reasons for the elevated incidence of paediatric malignancies are not thoroughly known, and can't

be elucidated entirely by the influx of improved diagnostic skills or genetics (13). There have been various environmental factors linked with childhood cancer. Ionizing radiation is one. It has been shown to elevate the risk of leukaemia and other malignancies in children, as epidemiological studies of children who were exposed before or after birth to emissions from the atomic explosives released in 1945 on Japan, or to therapeutic or diagnostic radiation, indicate (8).

Certain infections are also risk factors for developing childhood cancers. Viruses associated with cancer are known as oncoviruses. Examples are Epstein-Barr virus (EBV) linked with Burkitt's lymphoma, Hepatitis B virus (HBV) with liver carcinoma and Human immunodeficiency virus (HIV) with Kaposi's sarcoma (8). Variations in risk factor exposures contribute to the worldwide differences in the incidence of individual childhood cancers (8).

1.5 COMMON SIGNS AND SYMPTOMS OF CHILDHOOD CANCER (4)

Many clinical features of childhood malignancy are non-specific and mimic many other childhood diseases. This therefore requires HCWs to have an elevated index of suspicion to detect malignancy early (4). Some of the nonspecific clinical features include the following: (4)

- Continued, unexplained weight loss
- Recurrent/persistent fevers of unknown origin
- Constant tiredness or noticeable paleness
- Development of excessive bruising, bleeding, or rash
- Increased swelling or persistent pain in bones, joints, back, or legs
- Lump/mass, especially in the abdomen, neck, chest, pelvis, or armpits
- Rapidly growing mass on the jaw
- A mass in the abdomen with/without bloody urine
- Headaches, often with early morning vomiting

A team of physicians working in paediatric oncology in South Africa created and distributed the Saint SILUAN early warning signs of childhood cancer mnemonic so as to accentuate rapid diagnosis and timely referral of children with cancer. The physicians had been tasked with coming

up with a compilation of the early clinical features of malignancy in children to be utilized at the primary healthcare level and for the community. A list was therefore put together with the name Saint SILUAN warning signs and symptoms of cancer in children (14).

These are **(1) S**—Seek medical help early for persistent symptoms; **(2) I**—Eye: White spot in the eye, new squint, new blindness, bulging eyeball; **(3) L**—Lump: Abdomen and pelvis, head and neck, limbs, testes, glands; **(4) U**—Unexplained: Prolonged fever of over two weeks, loss of weight, pallor, fatigue, easy bruising, or bleeding; **(5) A**—Aching: Bones, joints, back, and easy fractures; **(6) N**—Neurological signs: Change or deterioration in walk, balance, or speech, regression of milestones, headache for more than a week with or without vomiting, enlarging head (14).

This mnemonic contains clinical features of over 80 per cent of childhood malignancies and has been adopted as an effective tool by the International Society of Pediatric Oncology (SIOP) to improve diagnosis and referrals (14). Following recognition of these signs along with supporting basic investigations, as per the Kenya health strategic and investment plan III (2013-2017) at both level 3 and 4 facilities the expected practice is to refer the patient to a tertiary care facility as the definitive diagnosis and management cannot be done at these lower-level facilities.

However, it is noted that 80 per cent of cases reported in the country are diagnosed at a late stage when not much can be done for cure (4). This is partly because of the inadequate knowledge of signs and symptoms of cancer, insufficient screening systems, deficient diagnostic facilities and poorly structured referral facilities (4). Late diagnosis along with the shortage and uneven distribution of cancer detection and treatment facilities, staff, and equipment lead to the high mortality rate and inequality (4).

1.6 KENYA'S HEALTH WORKFORCE

In 2010, a new constitution was passed in Kenya that introduced 47 semi-autonomous county governments, with substantial transfer of responsibility for health service delivery from the central government to these counties (15). In the health sector, county governments are assigned essential health service delivery, while health policy is retained in the national government, technical assistance to counties and management of national referral health facilities (15).

The WHOs, Sustainable Development Goals (SDGs) index threshold is 4.45 skilled health workers (physicians and nurses/midwives) per 1000 population (16). As per the Kenya Health workforce report 2015, most of the HCWs in the nation are nursing officers followed by clinical officers and the minority are doctors. The ratio of these HCWs to the populace differs by county (17). The national proportion of nurses in Kenya to the population is 8.3 per 10,000. Nairobi county has the highest ratio of nurses at 9.7 per 10,000.The national proportion of active clinical officers to the populace is 2.7 per 10,000. Nairobi county is at 0.8 per 10,000. The national proportion of medical doctors to the populace is 1.5 per 10,000. Nairobi county leads with 9.5 doctors per 10,000. Of the 5,660 retained medical doctors in 2015, 2,089 are consultants, of which 295 are paediatricians (17).

Kenya has scarce cancer specialists, and these are located in a handful facilities in Nairobi (18). This makes it hard for most of the populace to access services for cancer management, leading to prolonged waiting times resulting in potentially curable cancers progressing to incurable stages. This unfortunate situation is so because the infrastructure for cancer treatment in Kenya is deficient and some cancer care options are not readily available which require some Kenyans to pursue cancer management overseas (18).

1.7 HOSPITAL CLASSIFICATION IN KENYA

Table 1: MoH: Service Delivery Levels

National Health Sector Strategic Plan II (2005-2010) (19)	***Kenya Health Sector Strategic and Investment Plan III (2012-2017)*** (20)
Level 1 – Community	Tier 1: Community
Level 2 – Dispensaries	Tier 2: Primary Care level – Previous KEPH levels 2 and 3
Level 3 – Health centres	
Level 4 – District referral hospitals	Tier 3: County level – Previous KEPH level 4
Level 5 – Provincial referral hospitals	Tier 4: National level – Previous KEPH levels 5 and 6
Level 6 – National referral hospitals	

1.7.1 Organization of health services

Organization is into 3 service unit classifications – community level, primary care facilities and hospitals. There are sub classifications within each of these, as shown in the figure below (20).

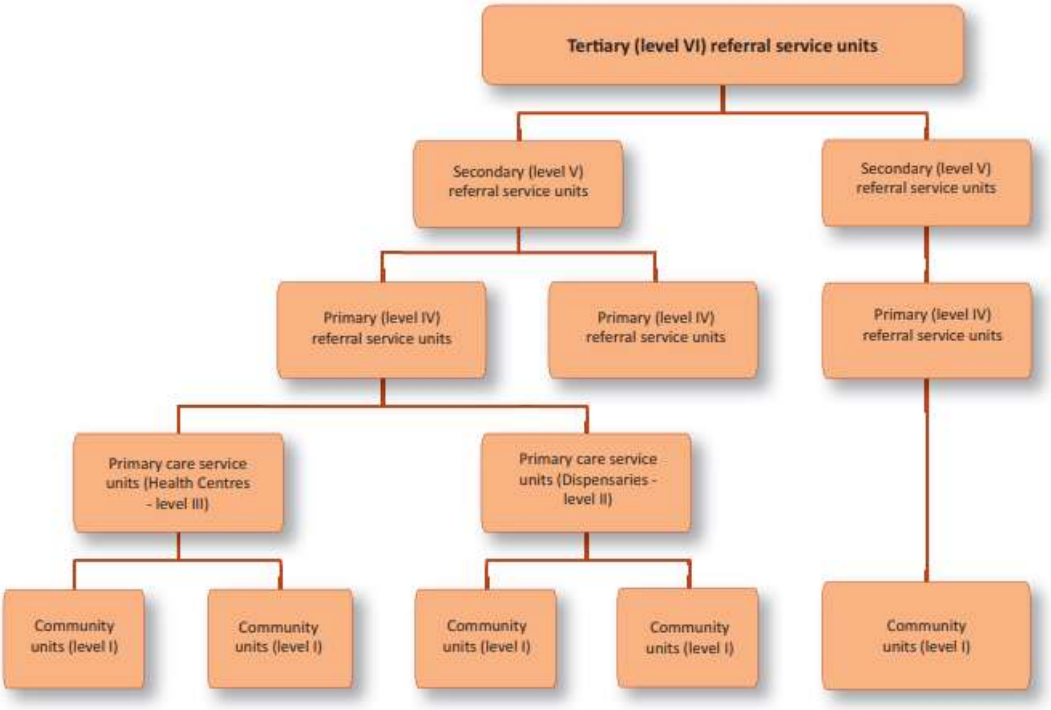

Figure 1: Organization of health services (Kenya Health Sector Strategic and Investment Plan III (2012-2017)

According to the Kenya Health Sector Strategic and Investment Plan (KHSSIP) III (2012-2017), county health services are formed around 3 levels of care: community, primary care, and referral services. Primary care service units are either dispensaries, mobile clinics or health centres for public and private providers. Hospitals focus on management of referral care, and are of 3 types: primary, secondary, or tertiary referral units. The complexity of services increase from primary to tertiary referral units. The primary referral service includes all level four hospitals, which are referred to as County Referral Hospitals (20).

As per the KHSSIP III (2012-2017), level 3 hospitals should have the following: 2 medical officers, 6 general clinical officers, 1 paediatric clinical officer, 8 Kenya registered community health nurses (KRCHN), and 2 Kenya registered nurses (KRN) (20), while level 4 facilities should have

2 pediatricians, 16 medical officers, 30 general clinical officers, 2 paediatric clinical officers, 50 KRCHN, 20 KRN, 2 paediatric nurses, 2 oncology nurses and 4 palliative care nurses (20).

In Kenya, however, the overall figure of HCWs employed as of now in the county health departments as well as in the public, faith-based organization and private health facilities is approximated at 31,412 (23). Such figures are well below the requirements of 138,266 HCWs according to the MoH's norms and standards guidelines. This therefore means that staffing of levels 3 and 4 hospitals is less than the recommendation. Shortage of personnel negatively affects the affordability and quality of service offered (21).

As per the KHSSIP III (2013-2017), the guidelines on the recommended service package including screening, laboratory and radiological tests that should be available at each of the health system levels are as shown in table 2 and 3 below. (20)

Table 2: KEPH interventions for reversing rising burden of NCDs by level of care

Services	Interventions	Lowest level for provision
Institutional Screening for NCD's	Blood Sugar testing	3
	Routine Blood Pressure measurement for all adults at the OPD	2
	Routine Body Mass Index (weight and height) measurement for all outpatients	2
	Cervical cancer screening for all women in the RH age group	4
	Faecal occult blood testing for bowel cancers	4
	Breast cancer screening for all women over 18 years	5
	Lung Function Testing	4
	Lipid profiling	4
	Annual prostate examination for all men over 50 years	4
	Screening for sickle cell anaemia (group?)	4

Table 3: KEPH interventions for improving person centred essential health services

Services	Interventions	Lowest level for provision
Clinical laboratory	Haematology*(Hb, RBC/WBC counts, hematocrit, peripheral film)*	3
	Pregnancy test	4
	Bleeding and coagulation time	4
	Blood grouping with Rh factors	4
	Parasitology *(RDT)*	2
	Hepatitis B and C tests	4
	Bacteriology *(ZN staining, Alberts staining, Gram Staining)* microscopy	3
	ELISA tests	3
	Widal tests	4
	CD 4 count	4
	PCR tests	5
	Viral culture	6
	Agglutination tests	4
	Urinalysis	3
	Liver Function Tests	4
	Renal Function Tests	4
	Blood gases	5
	Cardiac enzymes	5
	Cholesterol tests (Total / Differential)	4
	Blood culture	4
	Blood sugar	2
	Semen analysis	4
	Fecal Occult Blood testing	4
	Tumour markers *(PSA, Bence Jones protein, CA125, cytology, biopsy examinations)*	5
	Histopathology (FNA, Tru cut, Incision or excision) and cytology	5
	Micro nutrient test	4
	Cerebro Spinal Fluid analysis *(culture, biochemistry, cytology)*	4
Specialized laboratory	DNA testing	6
	Food analysis	6
	Water analysis	6
	Blood analysis *(alcohol, drug)*	6
	Stool testing *(e.g. polio)*	6
Radiology	Ultra sound scan	3
	X – ray	4
	Endoscopopy	4
	Laparascopy	4
	Computerized Tomography Scan	6
	Magnetic Resonance Imaging	6
	Radio-isotope scanning	6
	Angiography	6
	AVU / AVP	6
	Electro Encephalogram (EEG)	5
Operative	Outpatient operations	3
	Emergency operations	4
	General operations	4
	Specialized operations	5
Specialized therapy	Radiotherapy	5
	Chemotherapy	5
	Interventional Radiology	5

CHAPTER 2: LITERATURE REVIEW

It is noted that 80 per cent of cases reported in the country are diagnosed at a late stage when little can be done for cure (4). This is partly because of the inadequate knowledge of signs and symptoms of cancer, insufficient screening systems, deficient diagnostic facilities and poorly structured referral facilities. Late diagnosis along with the shortage and uneven distribution of cancer detection and treatment facilities, staff, and equipment lead to the high mortality rate and inequality (4).

2.1 DIAGNOSIS OF CHILDHOOD CANCER

Lags in the diagnosis of malignancy in the health care system led to the significant differences in deaths due to cancer among HICs and LMICs (9). Cancer in children is not easy to diagnose in the primary context: the index of suspicion is typically depressed due to the disease being relatively rare in children, the clinical features of cancer in children tend to not be specific and are similar to those of typical paediatric conditions (fever, pain, headache, and vomiting) and thus may hinder diagnosis (22).

In a few studies, lag time — time from start of symptoms and diagnosis — has been assessed worldwide including in Africa. The main findings have been that physician or health system lag time is much more than patient lag time in majority of the studies. Among other factors, inadequacy of perception of the early clinical features of paediatric malignancies among HCWs was documented as a factor in health system delays in diagnosis and consequently management (18).

In a cross-sectional study looking at factors influencing time to diagnosis and treatment among paediatric oncology patients in a hospital in Kenya, parents of 99 childhood cancer patients were interviewed and Njuguna et al found median patient delay (4 days) to be much less than healthcare system delay (87 days). In the healthcare system delay, median diagnosis delay (94 days) was found to be much more than median treatment delay (6 days). The researchers recommended in-service trainings for health workers who are already working (23).

Similarly, researchers at the University College Hospital (UCH), in Ibadan, Nigeria, found median patient lag time to be 2 weeks compared to 8 weeks of median physician lag time. Ninety-one children were studied in total. Delayed diagnosis of paediatric malignancy was found to be an

important problem. Training of health workers on early presentation and diagnosis was suggested (24).

In a single centre cross-sectional study on 138 children diagnosed with malignancy at the Pediatric Oncology Unit of Mansoura University in Egypt, median health system delay (27 days) was found to be nine times the median patient delay (3 days). Of the health system delays, median referral delay was 14.5 days, median diagnostic delay was 12 days and median treatment delay was 1 day. An initial misdiagnosis of 116 patients was made. Provisional diagnoses ranged from common colds, gastroenteritis to osteomyelitis to elucidate symptoms like fever, abdominal symptoms, and bone pain, among others. Clinical signs such as pallor were diagnosed as iron deficiency anaemia. Employment of continuous medical education (CME) for HCWs and specialty medical training on paediatric cancers as well as the form of cancer presentation, was suggested by the researchers (25).

Studies beyond Africa also had the same results. Patient delay was found to be significantly shorter than healthcare system delay. This was evident in a study carried out at an Indonesian hospital where guardians of 145 minors with malignancy were questioned. Median healthcare system delay (49 days) was found to be almost five times median patient delay (5 days). The researchers concluded that HCWs need education to enhance awareness of cancer symptoms and quicken diagnosis (26).

In a systematic review of twenty-three studies carried out worldwide on diagnosis delays in paediatric malignancy, it was discovered that the pattern was typically for physician delays to be more than patient delays. The review found that the correct specialist can take timely action to minimize delay. They concluded that the general practitioner can reduce lag times by raising alertness and awareness of cancer (27).

Table 4 below summarizes studies done on diagnostic delays of paediatric childhood cancers. These studies suggest that patients seek medical care earlier on when symptoms present but are failed by the healthcare system in getting an early diagnosis and consequently treatment.

Table 4: Literature on Diagnostic Delays of Paediatric Childhood Cancers

Author and Title	Study Design and Population	Results
Njuguna F, et al. Factors influencing time to diagnosis and treatment among pediatric oncology patients in **Kenya.**	Cross-sectional N = parents of 99 childhood cancer patients	Median total delay - 102 days Median patient delay - 4 days Median healthcare system delay - 87 days Median diagnosis delay – 94 days Median treatment delay – 6 days
Brown BJ, et al A Prospective Study on the Causes of Delayed Diagnosis of Childhood Cancer in Ibadan, **Nigeria.**	Prospective and observational N = 91 children	Median parent lag time - 2.0 weeks Median health system/physician lag time - 8.0 weeks Median overall lag time - 15.5 weeks
Abdelmabood S, et al Delays in diagnosis and treatment among children with cancer: **Egypt**ian perspective.	Cross-sectional N = 138 children	Median total delay - 37 days, Median patient/parent delay - 3 days Median physician delay - 28 days
Handayani K, et al. Delays in diagnosis and treatment of childhood cancer in **Indonesia.**	Cross-sectional N = parents of 145 children	Median total delay - 70 days Median healthcare system delay - 49 days Median patient delay - 5 days
Dang-Tan T, et al Diagnosis delays in childhood cancer: A review	Review 23 published studies	Generally, the tendency was for physician delays to be longer than patient delays.

2.2 KNOWLEDGE AND PRACTICES OF HEALTHCARE WORKERS ON CHILDHOOD CANCER

Even though a number of studies have been done on the factors influencing diagnostic delays in childhood cancer and health system delay found to be a major contributing factor, few studies on the knowledge and practices of childhood cancer especially among healthcare providers have been done.

One cross-sectional study done in level four hospitals in Western Kenya on the knowledge, attitudes and practices of 238 HCWs in Western Kenya found that 47.2% of them had poor knowledge of common clinical features of peadiatric cancers. The researcher interviewed nurses, clinical officers and doctors on various aspects of childhood cancer and knowledge of common clinical features which lead to diagnosis was found to be wanting among the nurses and the clinical officers which is worrying because they are the initial contact for majority of the patients who seek care at the primary health facilities. The recommendation was made to exert effort to improve knowledge on the clinic features of paediatric malignancy among all healthcare providers especially the clinical officers and the nurses and the staff should be accorded opportunities for training on childhood cancer management in established oncology units so as to improve their practice (28). In the same study, majority of the HCWs reported to having never participated in the management of child with cancer. Of those who participated, 58.4%reported participation in taking history and doing physical examination, 51.9% reported participation in carrying out lab investigations and 62.3% reported participation in referral (28).

At one university in South Africa (SA), researchers assessed 84 medical students' knowledge of early warning signs of childhood cancer. The study showed poor identification of signs of childhood cancers with CNS cancers being least identifiable. They advocated for heightened continuous exposure to paediatric oncology in medical schools and enhanced post-school awareness programs to enhance timely referrals (29).

Among 240 final year undergraduate medical students from all over South India, Scott et al looked at the knowledge, attitude and awareness of childhood malignancy. They found that 65.5 per cent of students felt that their childhood malignancy knowledge didn't make them capable of suspecting and referring aptly during their practice. With regard to the issue of which factor contributed the

most to the lack of adequate management of paediatric malignancy, 29.6 per cent of them thought that the leading cause was late diagnosis and referral. More than 80 per cent felt that their curriculum needed to improve paediatric oncology teaching. The researchers concluded that there was lack of confidence among future physicians in detecting and treating malignancies in childhood (30).

In Brazil, Workman et al assessed the knowledge of signs and symptoms of paediatric malignancy among the community health workers there. The study revealed that although the participants were aware of the need to refer a child thought to have a malignancy to a doctor, their knowledge of the early clinical features was quite minimal (31).

In a study in Bangladesh assessing cancer related knowledge, attitude, and practice among community health care providers and health assistants in rural Bangladesh, 54.15% of the respondents had good or above average score in the knowledge section while in the practice section 65.54% of respondents were found to have good practices. (32)

The following table 5 below summarizes studies done across the globe on knowledge and practices of HCWs and medical students on paediatric childhood cancers. The studies worryingly reveal a wanting level of knowledge and practice among these cohorts.

Table 5: Literature on Knowledge and Practices of Healthcare Workers on Paediatric Childhood Cancers

Author and Title	Study design and Population	Results
Ronoh EC. Knowledge, Attitudes and Practices of Healthcare Providers in Level Four Hospitals of **Western Kenya** Towards Childhood Cancer.	Cross-sectional study. N = 238 healthcare providers	Knowledge on common clinical features Poor - 47.2% Good - 23.2% Very good - 24.4% Excellent - 5.2% 36.6% had ever participated in the management of child with cancer with 62.3% reporting participation in referral.

Tapela NM, et al. A step toward timely referral and early diagnosis of cancer: Implementation and impact on knowledge of a primary care-based training program in **Botswana.**	Interventional N = 176 healthcare providers	Overall performance increase of 16.8% after participation in training. 40.3% trainees achieved a score greater than 70% on the pretest, and 91.5% did so on the posttest.
Geel JA, et al. Enough is not enough: Medical students' knowledge of early warning signs of childhood cancer. **South Africa**	Cross-sectional N = 84 students	The study demonstrated a marked inconsistency between recall and recognition of signs of childhood cancer
Scott J, et al. Knowledge, attitude and awareness of childhood cancer among undergraduate medical students in **South India.**	Cross-sectional study N = 240 undergraduate medical students	65.5% felt that their knowledge of childhood cancer did not make them competent to suspect and refer appropriately during their practice.
Workman GM, et al Pediatric cancer knowledge: Assessment of knowledge of warning signs and symptoms for pediatric cancer among **Brazil**ian community health workers.	Cross-sectional N=community healthcare workers	Minimal level of knowledge of the early warning signs and symptoms of childhood cancer

Nazirum M, et al Cancer related knowledge, attitude, and practice among community health care providers and health assistants in rural **Bangladesh.**	Cross-sectional N = 325 community Health Care Providers (CHCP) and Health Assistants (HA)	54.15% had good or above average score in the knowledge section while in the practice section 65.54% were found to have good practices.

On factors associated with HCWs knowledge on cancer the Western Kenya study found that knowledge on general clinical features of childhood cancer was poor among clinical officers (COs) and nurses but much better with medical officers (MOs). Also, knowledge by site and gender was found to be statistically significant while Knowledge by age, length of practice and cadre was not found to be statistically significant. Knowledge among MOs and COs was higher as compared to nurses although there was no statistical difference between level of knowledge and carder in the study (28).

A systematic review by Liang G et al on interventions addressing barriers to delayed cancer diagnosis in LMICs found examples of barriers/challenges to early diagnosis include poor health literacy, poor health service coordination, and limited diagnostic or treatment services. (33)

2.3 LITERATURE REVIEW SUMMARY

The literature shows that delays in diagnosis of childhood cancer are majorly due to health systems delays which includes physician and other healthcare workers delays rather than patient delays in presentation to the facility. It also shows that healthcare workers have inadequate knowledge of paediatric cancers and inappropriate practices in diagnosis and management of the same. The literature also shows that the factors associated with knowledge on cancer among HCWs include cadre and place of practice and challenges to early diagnosis include poor health literacy, poor health service coordination, and limited diagnostic or treatment services.

CHAPTER 3: STUDY JUSTIFICATION, QUESTION AND OBJECTIVES

3.1 STUDY JUSTIFICATION

If diagnosed early and treated adequately, many childhood cancers are potentially curable (4). Prevention of most childhood malignancies is not feasible, and only by improving treatment outcomes can mortality be reduced (8).

Many of the signs and symptoms of childhood malignancies are not suitable for screening and the emphasis therefore is on early diagnosis, a fundamental goal in paediatric oncology, which results in better treatment outcomes (4). The goal is however not being achieved in LMICs as shown by the high mortality rate and low cure rate of childhood cancers in LMICs. Health system delays in diagnosis are a major contributor to these striking disparities as seen in various studies (9).

In the healthcare system delay, diagnosis delay has been shown to be significantly longer than treatment delay (25).

Cancer treatment centres in Kenya are in a few tertiary centres and referrals come through primary health workers, majority of whom see only a few childhood malignancies throughout their working lives (18). Because a high suspicion index is needed, some primary care professionals may not think of cancer as a possibility when presented with a patient, and months may be spent in fruitless management of other diseases. Such diagnosis delays result in late referrals at more progressed stages of the disease and a worse prognosis (8).

It's pertinent that HCWs are adequately equipped to recognize warning clinical features, investigate and/or refer appropriately and in a timely manner. However, because many children are referred with advanced cancer, there's a need to understand the barriers to early diagnosis at first contact (25).

A similar study done in Western Kenya only looked at healthcare workers in level 4 facilities. Primary level care however is at level 3 facilities and many patients seek care in these facilities first before being referred to higher level facilities. It's important therefore to assess the healthcare workers in level 3 facilities as well. Additionally, the study was done in a rural set up as opposed to the urban set up of Nairobi, therefore it would be beneficial to know whether there are any major differences in the healthcare workers' knowledge and practice of paediatric cancer in the two set ups.

Assessment of the level of knowledge and establishment of practices of HCWs in level three and level four facilities in Nairobi County with regards to clinical features of childhood malignancies would help in understanding some of the barriers to early diagnosis. The study may seek to know if knowledge is lacking before training or if the practice is wrong so that the training can be tailor-made to those who see the bulk of patients.

Studies done on diagnostic delays of paediatric childhood cancers suggest that patients seek medical care earlier on when symptoms present but are failed by the healthcare system in getting an early diagnosis and consequently treatment. So as to understand where the challenges are in terms of diagnosis, the results of the study will inform policies and standard operating procedures that would lead to early diagnosis.

Data generated from the study may be used by training institutions to develop appropriate curricula to guide training on cancer knowledge and practice.

3.2 STUDY QUESTION

What is the knowledge and practices of HCWs on early signs and symptoms of childhood cancers in levels three and four public healthcare facilities in Nairobi County?

3.3 STUDY OBJECTIVES

3.3.1 Primary Objective

1. To determine the level of knowledge and describe management practice of HCWs in levels three and four facilities in Nairobi County on early signs and symptoms of childhood cancers.

3.3.2 Secondary Objectives

1. To describe the relationship between the healthcare workers' socio-demographic characteristics and their knowledge and practices on childhood cancers.
2. To determine challenges faced in identifying suspected childhood cancer in level three facilities and in diagnosis of childhood cancer in level four facilities of Nairobi County.

CHAPTER 4: METHODOLOGY

4.1 STUDY DESIGN

This was a mixed method cross-sectional study. Quantitative and qualitative data collection was employed using predesigned structured questionnaires and Key Informant Interviews (KIIs) respectively. Mixed methods were used as the qualitative data enriched the quality of the study. The quantitative data was collected first and that informed further exploration on the subject using key informant interviews.

4.2 STUDY SITE

The study was done in level three and level four healthcare facilities in Nairobi County.

Level three facilities were selected because they are the lowest level of hospital category that has three of the cadres of healthcare providers that this study will target i.e., the medical, nursing and clinical officers.

Level four facilities were selected because in addition to the cadres in level three, they also have specialists that this study will target i.e., paediatricians in KIIs.

In addition, level three and four facilities are primary and secondary healthcare facilities that refer their patients to tertiary healthcare facilities where cancer is diagnosed and managed.

Nairobi County is the capital city of Kenya. It is divided into 17 sub-counties. As per the latest 2019 Census report, Nairobi has a population of 4,397,073. A high percentage of the population is made up of children and adolescents aged 0-19 years (34). 126 of 681 health facilities in the county are publicly owned comprising of 4 county referral hospitals, 41 health centres and 81 dispensaries (35).

Once the study was approved by the UoN-KNH Ethics and Research Committee (ERC), it was carried out at the level 3 and 4 facilities of Nairobi County over a period of 3 months.

The study was carried out in 14 health centres (level three) out of the 41 in the county. These were randomly selected from the sub counties which were randomly sampled for the study.

The level four facilities in which the study was carried out in were Mbagathi County Hospital and Mama Lucy Kibaki Hospital (MLKH). These 2 were purposefully selected out of the 4 level four facilities in the county as they have the largest numbers of healthcare workers relevant to the study.

Mbagathi County Hospital is a county referral hospital in Nairobi County under the Nairobi County government. Per preliminary site survey, the hospital is staffed with 5 paediatricians, 9 medical officers, 5 clinical officers and 32 nurses. This is a total of 51 healthcare workers.

Mama Lucy Kibaki Hospital (MLKH) is a county referral hospital under the Nairobi County government. It's found in the eastern part of Nairobi in Embakasi division. Per preliminary site survey, the hospital is staffed with 3 paediatricians, 7 medical officers, 9 clinical officers and 29 nurses. This is a total of 48 healthcare workers

According to the Kenya health Service Availability and Readiness Assessment Mapping (SARAM) report, the minimum number of staff currently working in a health centre (level 3) are 2 clinical officers and 4 nurses (36). This is a total of 6 healthcare workers per facility.

4.3 STUDY POPULATION

The study population was HCWs in various departments where children aged 0-18 years are seen. This included paediatricians, MOs, COs and nurses as well as the in-charges of the facilities regardless of cadre.

Study population for the QUAL

The key informants that were interviewed were the personnel in-charge of the level 3 and level 4 facilities as well as the paediatricians in the level 4 facilities taking part in the study. These were purposefully selected since they are in charge and hence handle all the issues in their facilities therefore, they are likely to know more about the facility than the other healthcare workers. Their views then would be of value to the study.

4.4 INCLUSION AND EXCLUSION CRITERIA

4.4.1 Inclusion criteria

Any HCW that sees children from birth to 18 years regardless of the department they are in i.e., MOs, COs and nurses in various departments including paediatric, maternity outpatient and administration who gave informed consent.

In addition, in-charges and paediatricians of the selected facilities that consented to an interview were also included for key informant interviews.

4.4.2 Exclusion Criteria

1. HCWs on annual leave during the study period.

2. HCWs who had worked less than 3 months in the health facilities in Nairobi County.

3. Interns including medical officer interns, clinical officer interns and nursing officer interns.

4. All students who had not yet graduated.

4.5 SAMPLING TECHNIQUE

In order to achieve the desired number, the following sampling techniques were employed.

Of the 4 level four facilities in Nairobi County, 2 were purposefully selected i.e., Mama Lucy Kibaki Hospital (MLKH) and Mbagathi Hospital because they have the largest numbers of healthcare workers targeted in the study.

Nairobi has 17 sub counties with 41 government owned health centres (level 3) spread across the sub counties (35).

The sampling method used to select the health centres was a multistage sampling technique.

4.5.1 Sampling of Sub Counties

Step 1: Selection of sub counties. According to the WHO 30% of clusters can be used for sampling. Hence automated random sampling was done to select 6 out of the 17 sub counties (37).

Step 2: All the health centres in each of the six sub counties were listed.

Step3: To get the total number of health facilities the formula in Service Availability and Readiness Assessment (SARA) (37) was used to calculate the sample size for health centres to ensure a sufficient number.

$$n = \frac{\lceil [(Z^2 * p * q) - ME^2] \rceil}{\lceil ME^2 + Z^2 * p * q/N]] * d}$$

n = sample size

z = confidence level at 95% (1.96)

ME = margin of error (15%)

p = the anticipated proportion of facilities with the attribute of interest (0.5)

q = 1-p which is 0.5

N = population size of level 3 facilities in Nairobi County is 41

d = design effect which is 1.5

$$n = \frac{3.84*0.5*0.5+0.0225}{\frac{0.5}{41]*1.5}}$$

[0.0225+3.84∗0.5*

n= 14 health centres

Step 4: Random sampling was done to select the 14 health centres.

Step 5: Replacement facilities were selected after the initial 14 facilities had been selected. They were 10 as per the SARA document. They were selected randomly from the six sub counties after the initial sampling of the 14 facilities was done. All facilities from the remaining 6 sub counties were listed and random sampling done to select 10 facilities. These were to serve as the replacement facilities in case the sample size was not achieved.

4.5.2 Sampling of the health care workers

Step 1: In each of the selected 14 facilities including the level 4 facilities, a list of all staff per cadre working in the relevant departments was drawn.

Step 2: Once the level four hospitals and the health centres were selected, proportional sampling of the HCWs by cadre (MOs, COs and nurses) was done in each facility to get the proportional allocation of healthcare workers to be interviewed per cadre. Convenience sampling of these healthcare workers per cadre was then employed until the desired sample size per cadre was reached. Convenience sampling was employed as there was a shortage of HCWs at the facilities sampled because of industrial/labour disputes as well as effects of COVID 19 restrictions.

4.5.3 Selection of the KII

Key informant interviews were done in all the facilities that took part in the study. The interviewees were selected based on their position as managers of the level 3 facilities and consultants in the level 4 facilities. Since they are in charge, they handle all the issues in their facilities therefore they are likely to know more about the facility than the other healthcare workers.

4.6 SAMPLE SIZE

The total number of target healthcare workers in the selected facilities is 183. This includes 51 from MLKH, 48 from Mbagathi hospital and 84 from 14 health centres.

A minimum sample size was calculated. Since the sampling frame (total number of HCWs) was known, minimum sample size was calculated using the *formula for finite population* as follows;

$$n = N \Big/ [1 + N(e)^2]$$

Where n = desired sample size,

N = population size (183)

e = accepted level of error taking alpha as 0.05.

Calculating sample size yields the following;

$$n = 183 \Big/ [1+183(0.05)^2$$

$$n = 183 \Big/ 1.4875$$

***n* = 123**

Adjusting for 5% non-response yields

$$n = \frac{123}{0.95} = 129$$

4.7 STUDY VARIABLES

4.7.1 Dependent Variables

These was the level of knowledge on signs and symptoms of childhood cancers and the described practice on management of signs and symptoms of childhood cancers.

4.7.2 Independent Variables

These included age, sex, cadre, number of working years/years of experience, and the facility.

4.8 STUDY TOOLS

Self-administered questionnaires and KIIS were utilized. The questionnaire sample and the KII guide can be found attached in appendix 3 and 4 respectively. The questionnaires captured the sociodemographic and facility details in addition to the knowledge and practice of the HCWs on early signs and symptoms of childhood cancer.

Since there was no validated questionnaire to assess awareness of early signs and symptoms of childhood cancer as of now, the Saint SILUAN mnemonic was used as a basis for creating a questionnaire along with information from various literature on childhood cancer. Additionally, questions were adapted after adjustments from questionnaires used in other cancer studies (10,22,24).

The KIIs looked at the factors contributing to late referrals and late diagnosis of childhood cancer and also the challenges to early diagnosis of childhood cancer in the facilities taking part in the study. There was an interview guide for the questions to be asked. These are as per the attached appendix 4.

4.9 STUDY PROCEDURE

HCWs meeting the inclusion criteria were identified from paediatric and maternity wards as well as outpatient clinics. All eligible participants were given the consent forms and questionnaires. They proceeded to fill in the sociodemographic data as well as data on knowledge and practice of paediatric cancer. The consent forms contained a brief introduction about the study and described its purpose. They also contained information about safeguarding the participant's privacy and sharing of the study findings (appendix 1).

a) Quantitative research

Quantitative data was collected by way of self-administered questionnaires that assessed both the knowledge and the practice of the HCWs (appendix 3). Before the final study was launched, a small-scale pilot study was carried out on the target population for the purpose of validating the reliability of the questionnaires as well as familiarize the data collectors with the data collection process. This was done at facilities different from those that had been selected to participate in the study but within the same locality. This guaranteed the reliability of the research instrument.

Knowledge was assessed by asking questions on general knowledge of childhood cancer and knowledge signs and symptoms of childhood cancer while practice was assessed by asking questions on actual practice when faced with a child who has clinical features of childhood malignancy. This was assessed by use of questionnaires with questions specific to practice in terms of tests done for purposes of screening and diagnosis as well as management instituted which included treatment given or referrals made, if any. The questions were answered with a tick for the correct answer among several choices that were given, some of which were wrong and others correct.

b) Qualitative arm

Qualitative data was collected by way of KIIs. A topic guide with specific questions to be asked was used (appendix 4). We conducted a small- scale pilot study in facilities not selected for the purpose of validating the reliability of the guide, gauging the length of an interview and familiarizing ourselves with the interview process before the final study was launched. This was done at facilities different from those that were selected to participate in the study but in the same locality. This guaranteed the reliability of the research instrument.

We conducted 6 KIIs with facility team leaders, i.e., facility in-charges and paediatricians. The interviews were conducted both in person in the offices of the interviewees at a time that was convenient for each as well as over the phone. The interviews were recorded and transcribed verbatim, then the data was uploaded to dedoose (https://www.dedoose.com/) to manage the analysis. Two independent coders developed a codebook, and one was a primary coder while the other did secondary coding. They used deductive and inductive approaches to content analysis to

arrive at the themes Consent for audio recording was sought prior to the start of the interview with no markers of identification in the recording.

The interviews were done so as to get a broad picture of the challenges faced and reasons for delays in screening and diagnosis of paediatric malignancy. The questions asked included reasons for healthcare system delays in screening and diagnosis of paediatric malignancy, questions on the facilities and the personnel with regards to diagnosis of paediatric malignancy, challenges faced in diagnosis of paediatric malignancy in the facilities and suggestions for improvement in diagnosis of childhood cancer.

Validation of the recordings were done by assessing informants' knowledgeability, credibility, impartiality, willingness to respond, and presence of outsiders who may have inhibited their responses. Greater weight was given to information provided by more reliable informants. Interviewer or investigator bias was also checked.

c) Safety Measures

In view of Coronavirus disease 2019 (COVID 19) pandemic, safety measures were taken to eliminate potential transmission of the virus.

This included maintaining social distance of at least 1.5 metres between individuals, wearing of masks by all and hand hygiene with soap and water and/or alcohol hand sanitizer. Additionally, any persons with confirmed or suspected disease or signs and symptoms of the disease (cough, fever, difficulty breathing) were not allowed to participate in the study.

4.10 DATA MANAGEMENT AND ANALYSIS

Quantitative data analysis: The collected data was entered into a customized password protected Microsoft Excel spreadsheet. This was then exported to IBM™ SPSS version 24 for cleaning and analysis. All generated data sets were backed up in a password protected hard drive.

Sociodemographic characteristics are presented as frequencies and percentages for categorical variables. Continuous variables are described using medians and IQR if skewed and with means and standard deviations if normally distributed.

To answer the primary objective on level of knowledge, knowledge of signs and symptoms of childhood cancer is presented as percentages. The close-ended questions were analyzed as follows,

a correct response earned one mark and a wrong response earned no marks. Failure to tick any choice/or ticking 'I don't know' earned no mark. The score varied from question to question depending on the number of correct answers per question. Some questions had more than one correct response. The open-ended questions were analyzed as follows; any correct answer listed earned one mark and any wrong answer listed or any question not answered earned no mark. The limit of correct answers was set by the investigator depending on the particular question but the respondents were not limited in their responses. The score varied from question to question depending on the number of correct answers per question.

The scores were then transformed into percentages of correct answers for each question on the knowledge section. Knowledge was graded using a scale that was adopted and modified from a fairly similar study that was done in Nigeria (38). The scale was modified to the University of Nairobi (UoN), School of Medicine grading system as shown in Table 6 below (39). This grading system is also the same one that is used both by the medical and nursing schools in Kenya as well as by the Kenya National Examination Council.

Table 6: Scale for interpretation of level of knowledge

Score	**Interpretation**
<50%	Fail - Poor knowledge
50-64%	Pass - Good knowledge
>65-74%	Credit - Very good knowledge
>75%	Distinction - Excellent knowledge

To answer the primary objective on practice, in the practices section of the questionnaire, each question was analyzed separately to describe the practice employed by healthcare workers in the management of childhood cancer in terms of screening/diagnosis and referrals. Cross tabulations to help identify the patterns and the levels of knowledge and practices among the HCWs with regard to childhood cancer was performed.

To answer secondary objective 1, unadjusted and adjusted odds ratios were determined to weigh the strength of association among the independent and dependent variables. To test for statistically independent associations among the dependent and independent variables, regression analysis was

used. The 95% confidence intervals were determined, and statistical significance was set at a p-value of less than 0.05.

Qualitative data analysis: To answer secondary objective 2, broad ideas, concepts or phrases were coded. Themes were identified by looking at common responses to questions or repetitive words or phrases used by the respondents in the interviews. The presentation of the data was based on the themes and concepts that emerged. Quotes were also used in presentation of the collected data.

4.10.1 Study results dissemination plan

The results will be submitted to the Department of Paediatrics and Child Health, University of Nairobi as part of the requirements of the Master's Program in both hard and soft copies. Hard copies of the study will be sent to the University of Nairobi repository for storage. The findings will also be disseminated to KNH, presented in conferences and submitted for publication in peer reviewed scientific journals. They will also be submitted to the county health offices to be disseminated to the health workers through their facilities.

4.11 ETHICAL CONSIDERATIONS

1. Approval for conducting the study was obtained from the UoN-KNH ERC.
2. Consent and authorization were acquired from the department of health Nairobi County and relevant Medical Superintendents or in-charges of the study facilities.
3. A written informed consent explaining the details of the study was obtained from the study participants before enrolment. The consent forms are attached in appendices 1 and 2.
4. Only consenting participants were enrolled in the study.
5. Participants were informed of the voluntary nature of participation and they could opt out of the study at any time without being disadvantaged in any way.
6. For confidentiality, no personal identifiers were used and participants were issued with unique identification codes. The completed questionnaires were under lock and key and the computerized data was password protected. Only the principal investigator and the statistician have access to the completed questionnaires and the computerized data.

CHAPTER 5: RESULTS

There were 128 healthcare workers who participated in the survey. Of these, 98 (76.6%) of the practitioners worked at level 3 health facilities while 30 (23.4%) worked at level 4 health facilities in Nairobi County.

5.1 Sociodemographic characteristics of the practitioners

Majority of those interviewed were 34 years and below 78 (60.9%) with a mean age of 33.2 SD 7.1 with the youngest being 23 years and the oldest being 58 years. Majority of those interviewed were females 89(69.5%), Nursing Officers 77 (60.2%) and worked in pediatrics department 36 (28.1%). Majority had been in practice for less than 10 years 90 (70.3%) with a mean of 8.5 SD 6.3 with six months as the least time and 30 as the most years in practice. Only 12 (9.4%) had attended workshops on childhood cancers since leaving medical or nursing school.

Table 7: Sociodemographic characteristics of the health practitioners

Variable	Freq. (%)
Age	
≤ 34yrs	78(60.9%)
≥ 35 yrs	50(39.1%)
Gender	
Female	89(69.5%)
Male	39(30.5%)
Designation	
Nursing Officer	77(60.2%)
Clinical Officer	45(35.1%)
Medical Officer	6(4.7%)
Department	
Pediatrics	36(28.1%)
Internal Medicine	2(1.6%)
General Outpatient	35(27.3%)
Maternity	35(27.3%)
Administrative	20(15.8%)
Years of practice	
≤ 10yrs	90(70.3%)
>10 yrs	38(29.7%)
Training for childhood cancers	
Yes	12(9.4%)
No	116(90.6%)

5.2 General Knowledge of childhood cancers

Majority of health workers interviewed 119(92%) could correctly identify that childhood cancers were characterized by uncontrolled growth and spread of abnormal cells. The greatest risk factor for childhood cancers identified was genetics 104 (81.3%). Only 43 (33.9%) identified treatment with chemotherapy/radiotherapy for prior episodes and chromosomal abnormalities 46 (35.9%) as

risk factors. Some of the healthcare workers thought that living in urban areas 9 (7%) and living unhealthy lifestyles 57 (44.5%) were also risk factors of childhood cancers.

The most commonly known childhood cancers were Leukemia 120 (93.8%), Hodgkin's lymphomas 91(71.1%) and retinoblastomas 80 (62.5%). The least known childhood cancers were Rhabdomyosarcoma 36 (28.1%), Hepatoblastoma 42 (32.8%) and Osteosarcomas 46 (35.9%). There were health care providers who thought that colon 14 (10.9%), esophagus 14 (11.2%) prostate 6 (4.7%) and gastric 13 (10.2%) were childhood cancers as well. Majority knew that HIV increases chances of developing childhood cancers 103 (80.5%).

Table 8: Summary of knowledge of childhood cancers among the health practitioners

General knowledge on Childhood cancers	**Freq. (%)**
Definition: Childhood cancers are characterized by uncontrolled growth and spread of abnormal cells	119(92%)
Risk factors of childhood cancers	
Infections	70 (54.7%)
Genetics	104(81.3%)
Radiation	76 (59.4%)
Treatment with chemotherapy and radiation for prior cancer episode	43 (33.9%)
Chromosomal abnormalities e.g., Downs syndrome	46 (35.9%)
Types of childhood cancers	
Leukaemia	120 (93.8)
Hodgkin's lymphoma	91 (71.1%)
Retinoblastoma	80 (62.5%)
Brain tumors	79 (61.7%)
Non-Hodgkin's lymphoma	71 (55.5%)
Nephroblastoma	65 (50.8%)
Neuroblastoma	61 (47.7%)
Osteosarcoma	46(35.9%)a
Hepatoblastoma	42 (32.8%)
Rhabdomyosarcoma	36(28.1%)
HIV increases chances of developing childhood cancers	103(80.5%)

Table 9: Overall score on knowledge of signs and symptoms of childhood cancers

Poor knowledge (<50%)	66 (51.6%)

Good Knowledge (50-64%)	38 (29.7%)
Very good knowledge (65-74%)	9 (7%)
Excellent 9 (≥75%)	15 (11.7%)

The mean score was 47.25±1.24

The figure below shows the level of knowledge of signs and symptoms of childhood cancers amongst the HCWs. About half of them had poor knowledge while about 11% of them had excellent knowledge on the signs and symptoms of childhood cancer. i.e., half of them scored below 50% on the questions assessing knowledge on signs and symptoms of childhood cancer while 15 of them scored 75% and above

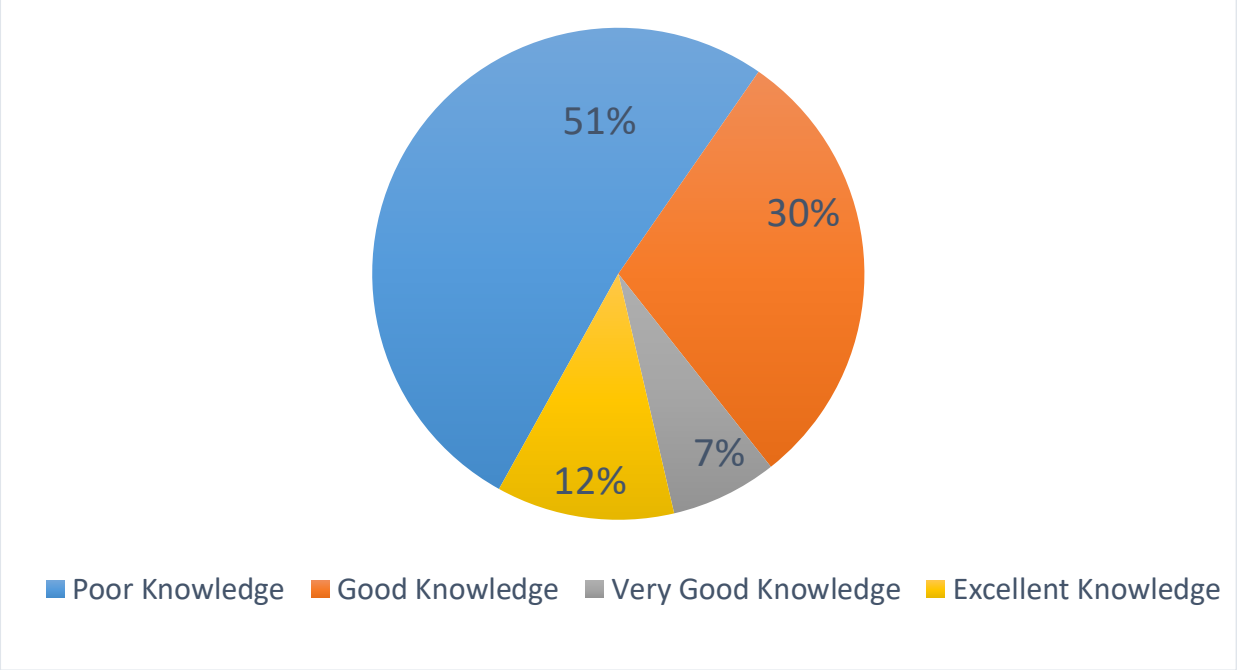

Figure 2: Knowledge on Signs and Symptoms of Childhood Cancer

5.3 Knowledge on early signs and symptoms of childhood cancers

5.3.1 Knowledge on early signs and symptoms of childhood cancers using SILUAN categorisation

In categorization as per SILUAN symptom categorization, the knowledge was as follows:

Table 10: **Knowledge on early signs and symptoms of childhood cancers using SILUAN categorisation**

Signs and symptoms	Nurses (N=77)	Clinical Officers (N=45)	Medical Officers (N=6)	No response	Total (N=128)
I					
Nystagmus	9(11.7%)	10(22.2%)	2	107(83.6%)	21(16.4%)
Diplopia	4(5.2%)	14(31.1%)	3	107(83.6%)	21(16.4%)
New squint	15(19.5%)	18(40%)	4	91(71.1%)	37(28.9%)
Proptosis	11(14.3%)	19(42.2%)	5	93(72.7%)	35(27.3%)
Leukocoria	13(16.9%)	16(35.5%)	5	94(73.4%)	34(26.6%)
L					
Adenopathy	39(50.6%)	22(45%)	6	61(47.7%)	67(52.3%)
Hepatosplenomegaly	39(50.6%)	27(60%)	5	57(44.5%)	71(55.5)
Swellings/mass	55(71.4%)	27(60%)	5	41(32%)	87(68%)
Abdominal distension	48(62.3%)	29(64.4%)	4	47(36.7%)	81(63.3%)
U					
Pallor	59(76.6%)	36(80%)	5	27(21.1%)	101(78.9%)
Prolonged unexplained fever	47(61%)	35(77.8%)	6	40(31.2%)	88(68.8%)
Weight loss	66(85.7%)	41(91.1%)	6	15(11.7%)	113(88.3%)
Easy bruising	32(41.6%)	24(53.3%)	5	59(46.1%)	69(53.9%)
Malaise/fatigue	57(74%)	30(66.7%)	6	35(27.3%)	93(72.7%)
Unexplained bleeding	33(42.9%)	28(62.2%)	5	62(48.4%)	66(51.6%)
A					
Joint pain	29(37.7%)	24(53.3%)	4	71(55.5%)	57(44.5%)
Bone pain	33(42.9%)	22(48.9%)	5	68(53.1%)	60(46.9%)
N					

Headache	32(41.6%)	22(48.9%)	4	70(54.7%)	58(45.3%)
Change in gait	26(33.8%)	21(46.7%)	4	78(61%)	50(39%)
Growth failure/Milestones regression	47(61%)	38(84.4%)	5	38(29.7%)	90(70.3%)
Change in behavior	22(28.6%)	17(37.8%)	6	80(64.8%)	45(35.2%)
Hemiplagia	16(20.8%)	16(35.6%)	4	92(71.9%)	36(28.1%)
Vomit	41(53.2%)	29(64.4%)	4	54(42.2%)	74(57.8%)
Seizure	33(42.9%)	32(71.1%)	5	58(45.3%)	70(54.7%)
Enlarging head	14(18.2%)	20(44.4%)	3	91(71.1%)	37(28.9%)

In general, the U symptoms were the most recognized and in specific unexplained weight loss was the most identifiable sign. On the other hand, the I symptoms were the least recognizable, specifically nystagmus and diplopia which are potential signs of a brain tumour, were the least recognizable.

The overall common symptom for I was New squint 37(28.9%). The common symptom among nurses was new squint 15(19.5), among clinicians was proptosis 19(42.2%) while 5 doctors stated proptosis and leukocoria as the most common symptoms.

The overall common symptom for L was Swelling/mass 87(68%). The common symptom among nurses was swelling/mass 55(71.4%) among clinicians was abdominal distention 29(64.4%) while all doctors stated abdominal distention as the most common symptoms.

The overall common symptom for U was weight loss 87(68%). The common symptom among nurses 66 (85.7%) and clinicians 41(91.1%) was weight loss while all doctors stated prolonged unexplained fever, weight loss and malaise/fatigue as the most common symptoms

The overall common symptom for A was Bone pain 60(46.9%). The common symptom among nurses 33(42.9%) and all doctors was bone pain while clinicians 24(53.3%) stated joint pain as the most common symptoms.

The overall common symptom for N was Growth failure/milestones regression 90(70.3%). The common symptom among nurses 47(61%) and clinicians 38(84.4%) was growth failure/milestones regression while all doctors stated change in behavior as the most common symptoms

Overall, amongst the nurses the most recognizable symptom was unexplained weight loss and the least was diplopia. Amongst the clinical officers, the most recognizable symptom was unexplained weight loss and the least was nystagmus. Amongst the doctors the most recognizable symptoms were unexplained weight loss, fatigue and adenopathy while the least was nystagmus.5.3.2 Clinical presentations of acute leukemia

5.3.2 Clinical presentation of acute leukaemia

Majority of the healthcare providers listed anemia 69 (53.9%), fever 58 (45.3%) and fatigue 53 (41.4%) as the most common clinical presentations of acute leukemia while vomiting and nausea

3 (2.3%) respectively were the least listed presentations. Only 28 (21.9%) of the healthcare workers could identify at least four signs and symptoms. 14 (10.9%) of the healthcare workers could not list any clinical presentation of acute leukemia. The figure below summarizes the findings

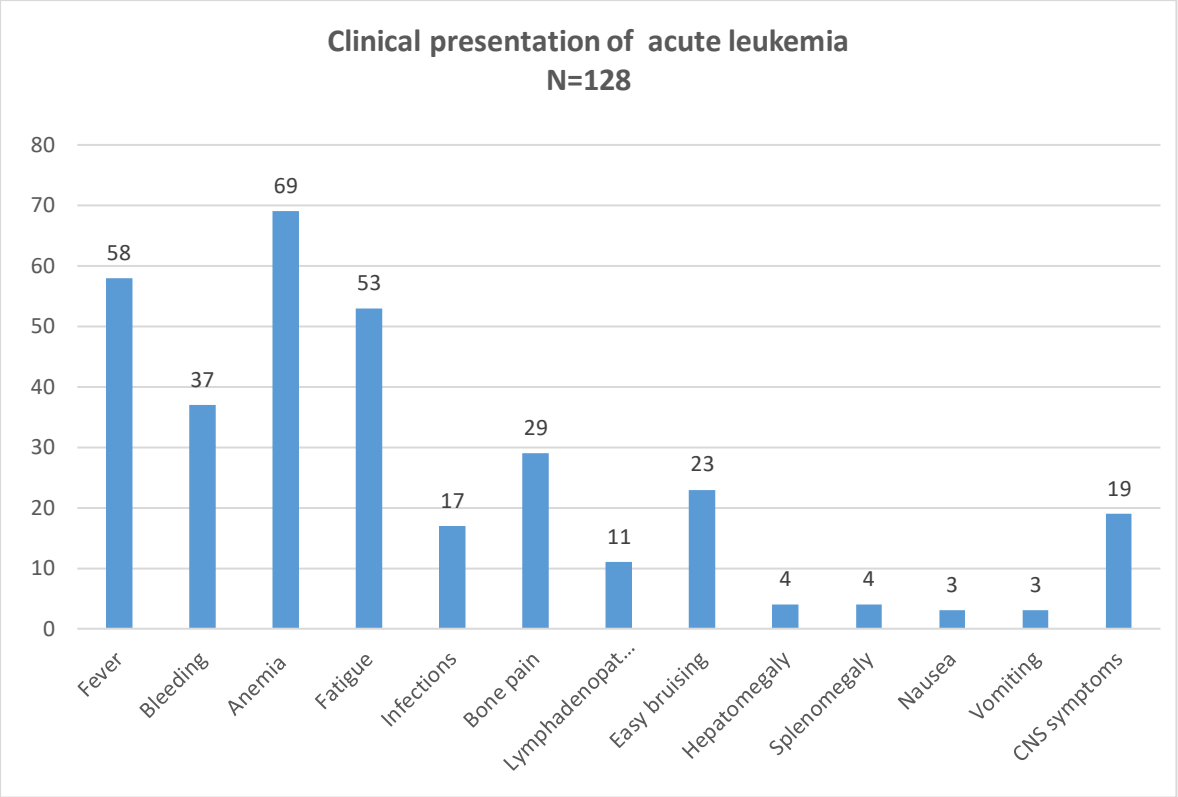

Figure 3: Clinical presentation of acute leukaemia

5.3.3 Clinical presentation of lymphomas

Majority of the healthcare providers listed adenopathy 69 (53.9%), fever 49 (38.3%) and weight loss 48 (37.5%) as the most common clinical presentations of lymphomas while vomiting 5 (3.9%) and nausea and infections 2 (1.6%) respectively were the least listed presentations. Only 36 (28.1%) of the healthcare workers could identify at least four signs and symptoms. 23 (18%) of the healthcare workers could not list any clinical presentation of lymphomas. The figure below summarizes the findings

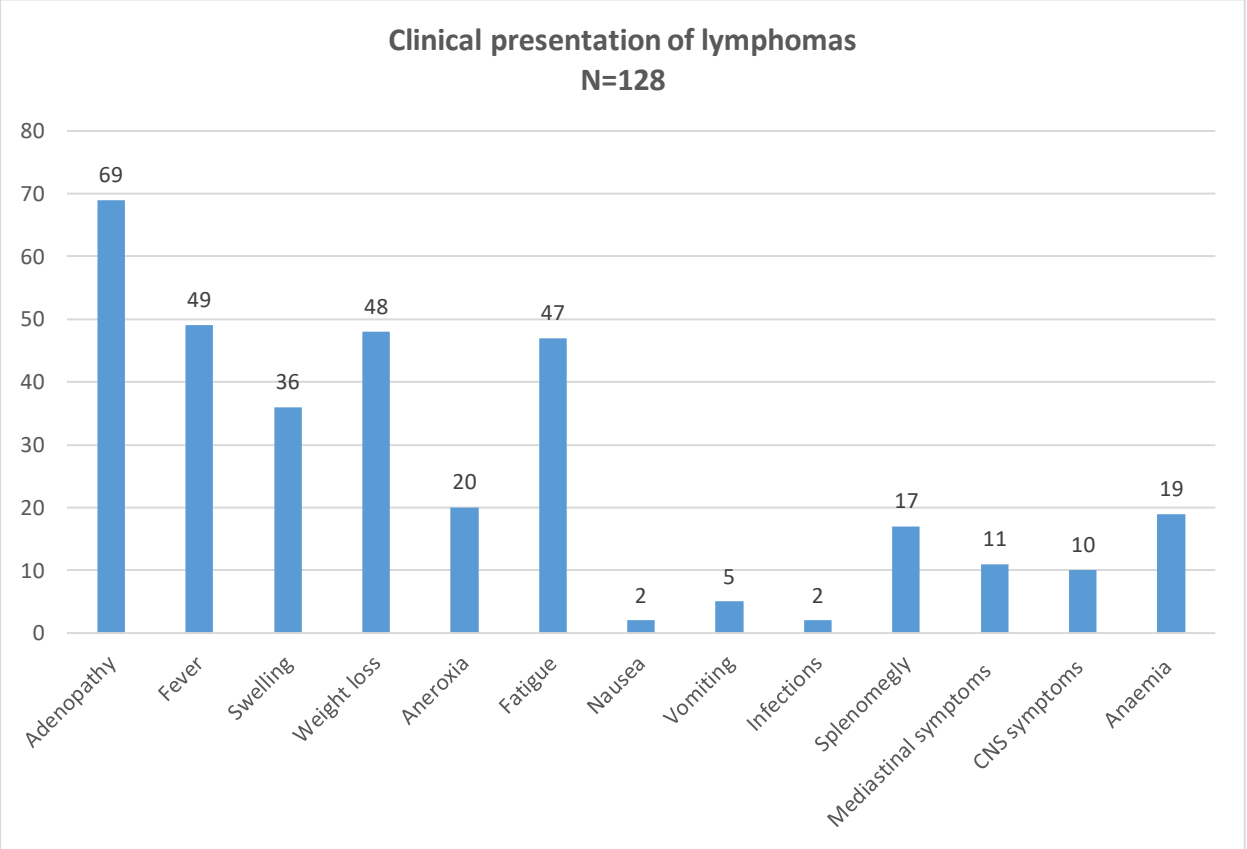

Figure 4: Clinical presentation of lymphoma

5.3.4 Clinical presentation of Wilm's tumor

Majority of the healthcare providers listed abdominal mass 56 (43.8%), hematuria 53 (41.4%) and fever 40 (31.3%) as the most common clinical presentations of Wilm's tumor while vomiting 13 (10.2%) and hypertension 15 (11.7%) were the least listed presentations. Only 27 (21.1%) of the healthcare workers could identify at least three signs and symptoms. 39 (30.5%) of the healthcare workers could not list any clinical presentation of Wilm's tumor. The figure below summarizes the findings.

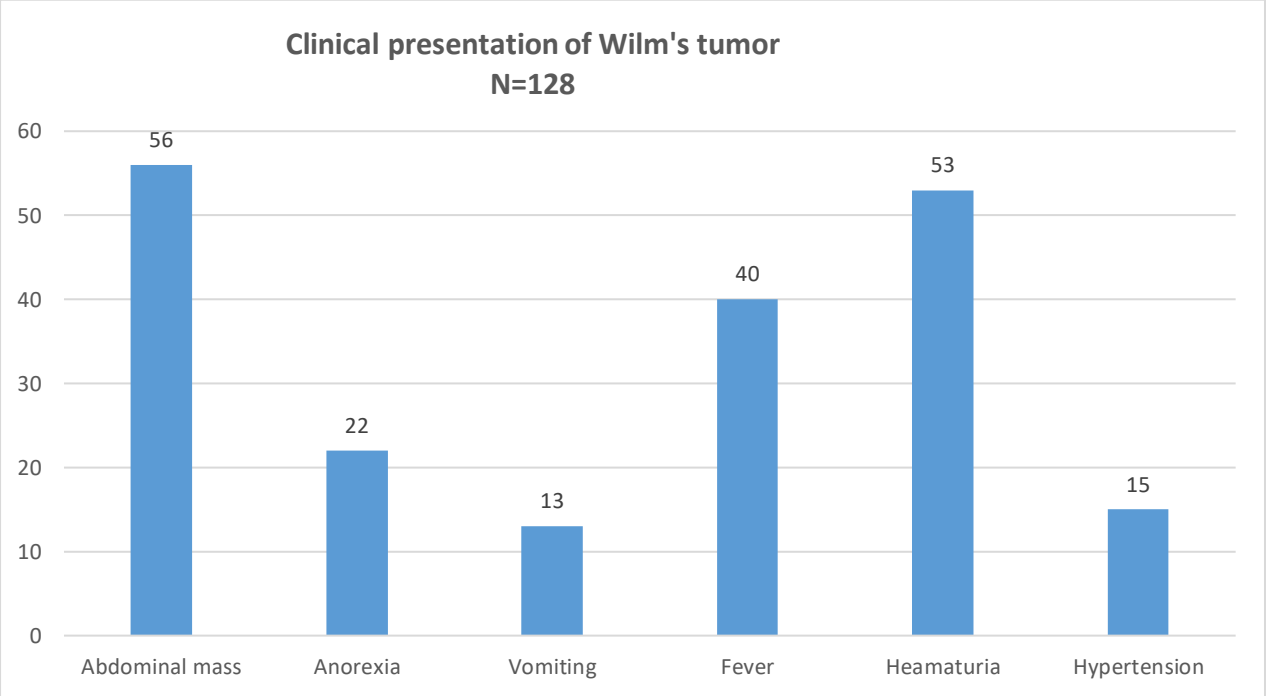

Figure 5: Clinical presentation of Wilm's tumor

5.3.5 Clinical presentation of retinoblastoma

Majority of the healthcare providers listed Leukocoria 61 (47.7%) and Proptosis 57 (44.5%) as the most common clinical presentations of retinoblastoma while Anisocoria 4 (3.1%) as the least listed presentations. 27 (21%) of the healthcare workers could not list any clinical presentation of retinoblastomas. The figure below summarizes the findings

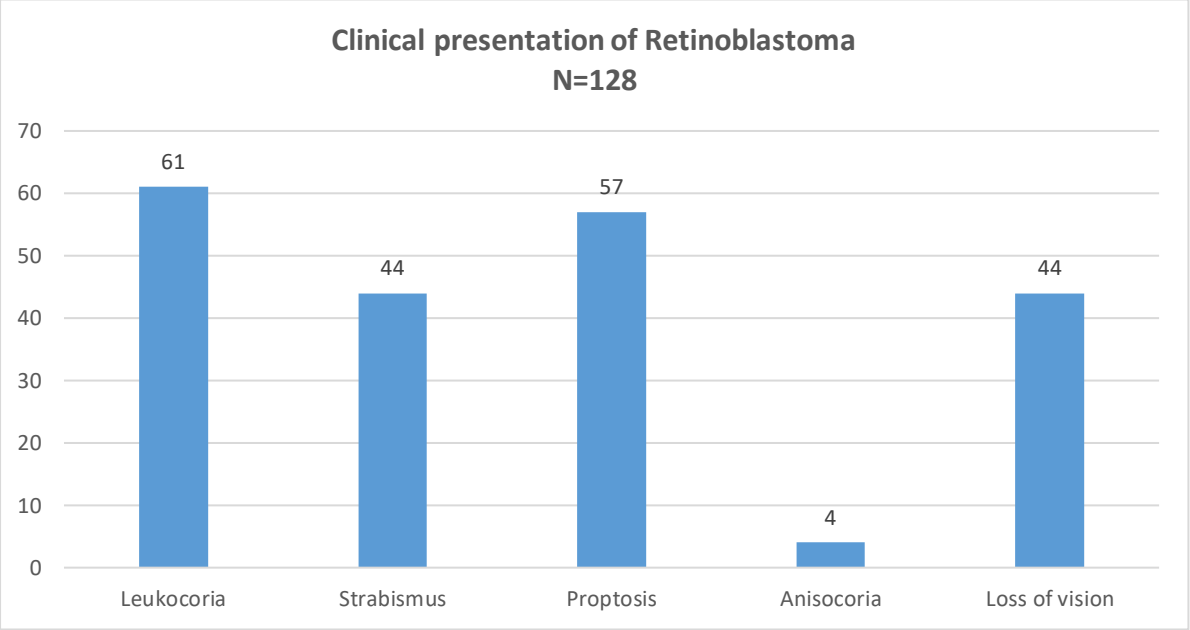

Figure 6: Clinical presentation of retinoblastoma

5.4 Practice on childhood cancer

This section focused on the most common presentations of childhood cancers and how HCWs managed the children they encountered with the symptoms both in their current and previous stations that may have been a higher-level facility. Only 35 (25%) of the healthcare practitioners interviewed had ever participated in the management of a child with cancer. Of these, most 20 (60.3%) were involved in referring of a child with suspected cancer.

When faced with a child with suspected signs and symptoms of childhood cancer, HCWs in both level 3 and 4 facilities are expected to appropriately investigate and refer patients with initial investigations pointing towards a malignancy, as childhood cancer diagnosis is confirmed and treated only in level 5 and/or 6 facilities. (18)

In the practice when encountered with certain signs and symptoms, selection of more than one option was acceptable. Majority of the practitioners 90 (70.3%) had encountered a child with an abdominal mass with many requesting for an abdominal scan. Only 35 (38.9%) referred the child to a surgeon. 122 (95.3%) had encountered a child with pallor with majority 103 (83.1%) doing a full hemogram first. Only 46 (37.1%) referred the child. 112 (87.5%) had encountered a child with unexplained prolonged fever and only 45 (38.8%) referred the child. Most 84 (72.4%) HCPs gave antipyretics. Of the 118 (92.2%) who encountered children with unexplained weight loss, half referred the child to a pediatrician. 90 (70.8%) had encountered children a child with drenching night sweats and enlarged lymph nodes with 51 (56%) referring the child. Most HCPs 69 (75.8%) investigated and treated for TB. From the above results, it shows that most HCPs did not refer children with these presentations early. The table below summarizes the findings.

Table 11: Practice in management of childhood cancers

Practice in management of childhood cancers	**Freq. (%)**
In your practice since graduation, have you ever participated in the management of a child with cancer	32 (25%)
In which of the following aspects of management of childhood cancer have you participated in	
Diagnosis	17 (53.1%)
Treatment	19 (59.3%)
Counselling	18 (56.3%)
Referral	20 (60.3%)
In your practice, have you encountered a child with an abdominal mass,	90 (70.3%)
What did you do	
Abdominal X-ray	15 (16.7%)
Abdominal U/S scan	65 (72.2%)
Abdominal CT scan	32 (35.6%)
Refer to a surgeon	35 (38.9%)
In your practice, have you encountered a child with pallor,	122 (95.3%)

What did you do	
Do a full hemogram	103 (83.1%)
Give haematenics	60 (40.4%)
Give blood transfusion	43 (34.7%)
Refer	46 (37.1%)
	112 (87.5%)
In your practice, have you encountered a child with unexplained prolonged fever,	
What did you do	
Give antibiotics	63 (54.3%)
Give antipyretics	84 (72.4%)
Do a full hemogram	72 (62.1%)
Do a septic screen	46 (39.7%)
Refer	45 (38.8%)
	118 (92.2%)
In your practice, have you encountered a child with anorexia and/or unexplained weight loss,	
What did you do	
Give appetite boosters	44 (37.3%)
Check for infection	73 (61.9%)
Advice mother on proper nutrition	63 (53.9%)
Refer to nutritionist	82 (70.1%)
Refer to pediatrician	59 (50%)
In your practice, have you encountered a child with drenching night sweats and enlarged lymph nodes,	90 (70.8%)
What did you do	
Investigate and treat for tuberculosis	69 (75.8%)
Do a lymph node biopsy	32 (35.2%)
Refer	51 (56%)

5.5 Factors associated with Knowledge on childhood cancers

Table 12: Factors associated with knowledge on childhood cancers

Variable	Poor Knowledge (<50%) (N=65)	Good knowledge (≥50%) (N=62)	COR (95%CI)	p value	AOR (95% CI)	p value
Designation						
Nursing Officer	38(58.4%)	38(61.3%)	1 (Ref.)		1 (Ref.)	
Clinical Officer	25(38.4%)	20(32.2%)	0.86(0.42,1.83)	0.723	1.64(0.67,2.98)	0.616
Medical Officer	2(3.2%)	4(6.5%)	3.4(2.17,8.93)	**0.005**	2.46(1.54,6.92)	**0.020**
Age						
≤34yrs	39(60%)	24(41.5%)	1 (Ref.)		1 (Ref.)	
≥35 yrs	26(40%)	38(58.5%)	2.69(0.88,6.31)	0.036	1.84(0.34,2.24)	0.052
Gender						
Female	48(73.8%)	40(64.5%)	1 (Ref.)		1 (Ref.)	
Male	33(26.1%)	22(35.5%)	0.71(0.26,1.97)	0.520	0.78(0.26,2.36)	0.662
Years of practice						
≤10yrs	44(67.7%)	45(72.6%)	1 (Ref.)		1 (Ref.)	
>10 yrs	21(32.3%)	17(27.4%)	1.94(0.77,4.86)	0.158	0.93(0.23,3.84)	0.920
Training						
No	59(90.7%)	55(88.7%)	1 (Ref.)		1 (Ref.)	
Yes	6(9.3%)	7(11.3%)	0.37(0.05,2.99)	0.350	0.25(0.02,2.64)	0.250
Type of facility						
Level 3	52(80%)	42(67.7%)	1 (Ref.)		1 (Ref.)	
Level 4	13(20%)	20(32.3%)	3.7(1.21,6.98)	**0.023**	2.84(1.02,7.92)	**0.040**

The above table shows factors associated with knowledge on childhood cancers. Designation (p=0.005), Age (p=0.036) and type of facility (p=0.023) were significantly associated with knowledge.

Medical doctors had 3.4 times higher odds of being knowledgeable about childhood cancers compared to nurses. Those who worked in level 4 facilities had 3.7 times higher odds of being

knowledgeable about childhood cancers compared to those who worked at level 3 facilities. Health practitioners aged 35 years and above had higher odds of being knowledgeable about childhood cancers compared to those who were below 35 years though this was not statistically significant.

Adjusting for other factors in the model, designation and type of facility were significantly associated with knowledge of childhood cancers.

Medical doctors had higher odds of being knowledgeable about childhood cancers compared to nurses AOR 2.4(95% CI; 1.54-6.92, *p*=0.020).

Those who worked in level 4 facilities had higher odds of odds of being knowledgeable about childhood cancers compared to those who worked at level 3 facilities AOR 2.84(95% CI; 1.02-7.92, *p*=0.040).

5.6 Challenges in identification and diagnosis of childhood cancer

The participants acknowledged that the health system challenges contributed significantly to the delayed diagnosis of childhood cancer. They further noted that at level 3 and 4 facilities the lack of capacity in terms of training and equipment was a major contributor to the delays. This lack of capacity subsequently resulted in the misdiagnosis of childhood cancers. The most these facilities were offering was referral to higher-level facilities whenever they suspected cancer. And even when referrals were done, they were not done in good time. Also, all the participants interviewed reported that while healthcare system delays were a major barrier to the diagnosis of childhood cancers, patient factors are also worth addressing.

5.6.1 Themes

1. There are hardly any cancer screening/diagnostic services at level 3 and 4 facilities

The key informant participants in this study described that level 3 and 4 facilities in their current state are deficient in capacity to screen or diagnose childhood cancers.

"We (level 3 facilities) only suspect but we cannot say that we have diagnosed, when we suspect we refer." KII2

"*Maybe they can only go to the point of maybe there is a high index of suspicion, and they refer to KNH. Because they can't do bone marrow, they can't do any screening tests, they do not have the capacity*" KII 6

Lack of these services was also linked to lack of funding to equip these facilities to provide screening and diagnosis of childhood cancers. The laboratories at these facilities cannot perform any cancer-related diagnostic tests.

"*There is a funding issue because when funding was there then the equipment will be there but without funding, you won't have equipment*." KII2

"*Our laboratory does not support, okay our laboratory does not support in the sense that a simple PBF is difficult to be done here, we don't have the mechanism to do a bone marrow, we don't do proper imaging like advanced CT scan MRI we don't do it here. So, we are sort of constrained in diagnosis"* KII3

2. HCWs in level 3 and 4 facilities lack training in cancer screening and diagnosis

Healthcare providers at level 3 and 4 facilities do not have the training to even do basic cancer screening yet majority of population seek services at these facilities. All the participant reported that to be a major hinderance and recommended that these HCWs need to be empowered.

"Basically, in our facilities level three, most of the staff, majority all of the staff lack training in cancer, and also, we have lack of seminars and workshops in the same field." KII 1

"We do not have the tests that should be done, the facilities are not advanced to that level, and then another one is lack of training we don't have enough trained personnel to handle cancer." KII4

"*Now, I think everything falls and the whole thing will just come back to the health worker having their eyes opened and that comes from training, because if you do not train the health worker and we keep emphasizing because we have emphasized so many other diseases, we have promoted them so much then we have forgotten some of the most important conditions that are actually cause or killers in our country*" KII5

3. HCWs also view patient/caregiver factors as a significant cause in the delay

While health system-related delays were substantial the participants reported that patient factors need attention. They noted that patient health-seeking behavior may delay presenting to care as patients seek help in alternative medicine and prayers.

"*So, delaying in presenting somebody for screening, they have gone round, they start at the chemist, then they go to low level facilities, they are treated for things which are not there. Maybe they go to the traditional healers before finally they decide to go to a higher-level facility"* KII 6

"Lack of knowledge by the parents and then drugs from other source, whenever they feel sick, they go for prayers if they are not feeling well" KII 4

And in other cases, socioeconomic factors contribute to delay in seeking care including when they have been referred to facilities that can screen and diagnose childhood cancers

"Apart from delayed referrals it could be social economic, social economic in the sense that you can't afford to reach to a health center or facility where you could probably be properly diagnosed. It can be cultural in the sense that people struggle with modern medicine still until today, so it could be cultural" KII 3

CHAPTER 6: DISCUSSION

6.1 Socio-demographics of the practitioners

Respondents in this study were majorly female (69.5%), and nurses (60.2%). This could be explained by nursing being perceived as a female profession from the time of the pioneer nurse Nightingale. The mean age of the respondents was akin to the study done in Nigeria that showed that the mean age in years was 37.5 ± 8.43838. (39)

6.2 General Knowledge of childhood cancers

Majority (92%) of the health care workers were able to pick out the correct definition of childhood cancer as shown by their choice of 'it is a group of disease characterized by uncontrolled growth and spread of abnormal cells'. This is similar to a study done in Western Kenya where 93.7% of HCWs were able to correctly pick out the correct definition of childhood cancer. (30)

On the knowledge of risk factors of childhood cancer, the greatest risk factor identified was genetics 104 (81.3%). This is comparable to the study in Western Kenya where 76.9% of the respondents reported inheritance/ genetics as a risk factor of childhood cancer. (30). This can be explained by the fact that the cause of childhood cancer is unknown. Some of the healthcare workers thought that living an unhealthy lifestyle 57 (44.5%) was a risk factor of childhood cancers. This can be explained by the fact that unhealthy living styles is a major risk factor for adult cancers and therefore some people may think that the same is true for childhood cancers.

The most commonly known childhood cancers were Leukemias 120 (93.8%). This is in line with and is explained by the GLOBOCAN 2018 report on childhood cancers in Kenya that reported that among new childhood cancers diagnoses in Kenya in 2018, leukaemia was the leading cancer diagnosed at 16.5%. (18). The least known childhood cancers were Rhabdomyosarcoma 36 (28.1%), Hepatoblastoma 42 (32.8%) and Osteosarcomas 46 (35.9%). This can be explained by the low incidence and prevalence of these cancers in Kenyan children as shown by the GLOBOCAN 2018 report. (18)

Majority knew that HIV increases chances of developing childhood cancers 103 80.5%). This is good given that there is evidence linking childhood cancer to HIV infection. (8)

6.3 Knowledge on early signs and symptoms of childhood cancers

The low level of knowledge on signs and symptoms of childhood cancer among HCWs with about half of the health workers scoring below 50 % (51.6%) is suggestive of inadequate exposure to cancer patients since many of the facilities lack the ability to screen/diagnose and treat these patients as well as low index of suspicion due to emphasis on communicable diseases and less on non-communicable diseases such as cancers. Despite efforts towards improving medical educations, it has been shown that healthcare professionals are not sufficiently educated about cancer risk factors, risk assessment and cancer prevention (41). The mean score on knowledge on signs and symptoms of childhood cancer was 47.25%. This is comparable to the one done in Western Kenya where poor knowledge on common clinical features among the HCWs was about 47% on average. The implication of this low level of knowledge on presentation is possible misdiagnosis and/or delayed diagnosis due to low index of suspicion contributing to poor outcome for the children with suspected cancer who are referred to the tertiary facility at an advanced stage of the disease.

In the SILUAN categorization of signs and symptoms of childhood cancer, The U symptoms in general were the most recognized and in specific unexplained weight loss was the most identifiable sign. This could be explained by the fact that this sign presents a bit later than the rest and so the child has been managed for other conditions by then. This is also a major symptom of NHL which is the second most prevalent cancer in Kenya. On the other hand, the I symptoms were the least recognizable, specifically nystagmus and diplopia which are potential signs of a brain tumour, were the least recognizable. This could be because most patients go directly to eye specialists of any cadre in cases of any eye symptoms thus the general practitioners are not exposed to the eye symptoms and when they are they refer to the eye specialists hence the low level of knowledge. The implication of this is late presentation and/or referral of patients with possible eye or brain tumour leading to late diagnosis and resulting in poor outcome contributing to the high burden of mortality of children with malignancies.

6.4 Practice on childhood cancer

Majority (75%) of the HCWs reported to having never participated in the management of a child with cancer in any form including diagnosis and/or referral. This is comparable to the study done in Western Kenya where 63.4% reported having never participated in the management of a child

with cancer with participation being highest among. In our study of those who had participated, 60.3% were involved in referring a child with suspected childhood cancer after initial investigations (e.g., full haemogram) that were done pointed towards a malignancy. This is also comparable to the study done in Western Kenya where 62.3% were involved in referring a child suspected to have cancer. This is a good practice as the facilities in which the study was carried out in do not have the capacity to manage childhood cancer therefore prompt referral is recommended as per the Kenya health strategic and investment plan III (2013-2017) (22) .

However, on the practice when encountered with possible signs and symptoms of childhood cancer, early referral rate for some of these symptoms was low. HCWs did not refer the children with these presentations early. Referrals were made later. They instead focused on managing the symptoms as well as other possible diagnoses. For example, 112 (87.5%) had encountered a child with unexplained prolonged fever and only 45 (38.8%) referred the child. Most 84 (72.4%) HCWs gave antipyretics. When encountered with a child with drenching night sweats and enlarged lymph nodes, most HCWs 69 (75.8%) investigated and treated for TB with about (56%) referring. This low early referral rate can be explained by a low index of suspicion among these HCWs who do not have any experience with childhood cancer diagnosis as well as the lack of adequate continuous medical education on the same as most reported to have never attended any workshop on childhood cancer. Late referrals and misdiagnosis contribute to poor outcomes of death in children with cancer for whom early treatment is key to cure and good outcomes. These findings can be compared to the study done in Egypt where an initial misdiagnosis of 84% of patients that were seen was made. Provisional diagnoses ranged from common colds, gastroenteritis to osteomyelitis to elucidate symptoms like fever, abdominal symptoms, and bone pain, among others. Clinical signs such as pallor were diagnosed as iron deficiency anaemia. Employment of continuous medical education (CME) for HCWs and specialty medical training on paediatric cancers as well as the form of cancer presentation, was suggested by the researchers

6.5 Factors associated with Knowledge on childhood cancers

Knowledge among MOs was higher as compared to NOs and it was statistically significant with a p-value of 0.020. This is comparable to the study done in Western Kenya where knowledge regarding childhood cancer was high among doctors and inadequate among nurses and clinical officers. This is explained by recognizing the fact that pre-service trainings are offered at different

levels for the 3 cadres(degree level for the MOs and mainly at college(diploma) level for COs and nurses. Therefore, the training curricular are likely to vary with regards to depth of content covered on this topic. In addition, doctors are tasked with diagnosis and treatment and are found in level 4 facilities which gives them an edge over the clinical officers who are mostly found in lower-level facilities with less diagnostic equipment and less patient flow and nurses whose work focuses more on supportive nursing care in the management of children with cancer. This could have contributed to the higher level of knowledge among medical officers as compared to clinical officers and nurses.

Working in a higher-level facility(level 4) was associated with good knowledge of childhood cancers. This is explained by having MOs who are more knowledgeable working in these level 4 facilities and not in level 3 facilities.

6.6 Challenges in identification and diagnosis of childhood cancer

The participants acknowledged that the health system challenges contributed significantly to the delayed diagnosis of childhood cancer. They further noted that at level 3 and 4 facilities the lack of capacity in terms of training and equipment was a major contributor to the delays. This lack of capacity subsequently can explain the misdiagnosis and/or delayed diagnosis of childhood cancers. These findings are comparable to the study done in Western Kenya where the HCWs felt helpless in attending to the patients due to resource limited settings without any cancer diagnostic services. This is also comparable to the systematic review by Liang G et al on interventions addressing barriers to delayed cancer diagnosis in LMICs where barriers/challenges to early diagnosis were identified as poor health literacy, poor health service coordination, and limited diagnostic or treatment services (34).

Also, all the participants interviewed reported that the patient's health seeking behaviour was poor as they presented to healthcare facilities late and therefore these patient factors are also worth addressing. This is in contrast to the study done by Njuguna et al amongst paediatric cancer patients in Kenya which found the mean patient delay to be significantly shorter to the health system delay in diagnosis and treatment (24)

CHAPTER 7: STUDY LIMITATIONS

1. Lack of a validated tool for assessing knowledge and practice of childhood cancers.
2. The sample size in this study is biased in favor of nurses because of relatively smaller number of other cadres in the facilities. This challenge was addressed by comparing the three groups separately in data analysis.
3. At the time of the study there was a shortage of HCWs in the facilities due to an ongoing industrial/labour dispute as well as the COVID 19 restrictions which forced us to do convenient sampling of HCWs as opposed to random sampling.
4. Some questionnaires were not filled in the presence of the investigator but the participants were asked not to refer from any literature, however there was no way of ensuring this.
5. The practice in this study is reported and not observed and participants may have reported what they know and not what they actually practice.

CHAPTER 8: CONCLUSIONS AND RECOMMENDATIONS

8.1 Conclusions

There was generally poor level of knowledge on childhood cancer among the HCWs though the knowledge on signs and symptoms among the MOs was satisfactory but insufficient among COs and nurses. Anaemia is the most known presentation and leukaemia is the most known childhood cancer among the HCWs. Fewer than half of HCWs had participated in the management of childhood cancers in any way including diagnosis and referral. Most would consider referring, when encountered with a child with possible signs and symptoms of childhood cancer but referrals are done late due to low index of suspicion.

There was significant association between the level of knowledge and cadre as well as level of knowledge and facility level. Challenges in suspecting, screening and diagnosis of childhood cancer include lack of training, lack of screening and diagnostic services and patient delay in presentation.

8.2 Recommendations

1. Efforts should be made to increase knowledge on the telltale signs and symptoms of childhood cancer among all HCWs especially the clinical officers and the nurses by way of continuous medical education and training workshops.
2. Posting of medical officers to level 3 facilities.
3. Provision of essential diagnostic equipment in the facilities as per the KHSIP III (2013-2017), guidelines.
4. Public health education to prevent delay in presentation to healthcare facilities should be done.

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CHAPTER 10: APPENDICES

10.1 APPENDIX 1: CONSENT FORM FOR PARTICIPATION IN THE STUDY

Dear participant, we are conducting a scientific study and would like to ask your voluntary participation in it. A questionnaire is provided for you to answer.

Study Title: **KNOWLEDGE AND PRACTICES OF HEALTHCARE WORKERS ON SIGNS AND SYMPTOMS OF CHILDHOOD CANCERS IN LEVELS THREE AND FOUR PUBLIC HEALTH FACILITIES IN NAIROBI COUNTY.**

Study background: Cancer is a group of conditions distinguished by unchecked proliferation and dissemination of aberrant cells arising from failure of the mechanisms that regulate normal cell growth and death, causing uncontrollable cell proliferation, degradation of surrounding tissues and dissemination of the disease to other parts of the body

Broad objectives: To determine the level of knowledge of HCWs in levels three and four facilities in Nairobi County on early signs and symptoms of childhood cancers and to determine practices of HCWs in levels three and four facilities in Nairobi County on early signs and symptoms of childhood cancers.

Study Procedures: This study involves getting information from the healthcare workers in level 3 and 4 facilities in Nairobi County about their understanding of general knowledge of childhood cancer and its signs and symptoms as well as practice of cancer management when faced with children with the signs and symptoms of childhood cancer, by use of **questionnaires** and key informant interviews. The questionnaires shall contain questions to be answered by the participants in an unrestricted amount of time without referring to any educational material.

Information will also be sought by **interviewing selected key informants** i.e. in-charges of facilities and consultants. They will be asked questions pertaining to their facilities and the personnel in their facilities with regards to childhood cancer. The interviews will be done in a

conducive, friendly environment. Notes as well as audio recording will be done by the interviewer during the interview with no personal identifiers. This will be done with the consent of the participant.

Voluntariness of participation: Participation is voluntary. We therefore request your permission to involve you in the study.

Benefits of participation: There are no direct benefits for participating in this study.

Risks pf participation: There are no risks for participating in the study.

Rights of Withdrawal: Refusing to participate in this study will have no consequences whatsoever. One may also withdraw from participation in the study at any time they wish with no consequences borne.

Confidentiality: No personal identifiers will be used. Your identity will remain absolutely confidential. All answers obtained will be considered privileged. These will be documented and analyzed anonymously. The researchers aim to publish this paper purely for academic and scientific purposes.

If you have any questions which you feel the investigator explaining to you has not handled or you would want another opinion, feel free to contact the Principal Investigator, Dr. Purity Nyaguthii Muhoro on 0726671571 or the lead supervisor, Dr. Boniface Osano on 0722646720.

For more information, you may also contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee, on 2726300 Ext. 44102, email uonknh_erc@uonbi.ac.ke.

I have understood the explanation given to me about this study and hereby give consent to take part in it.

Name of Participant: ……

Signature……... Date ……...

Name of investigator.....

Signature..... Date.....

10.2 APPENDIX 2: CONSENT FORM FOR KEY INFORMANTS

Dear participant, we are conducting a scientific study and would like to ask your voluntary participation in it. A questionnaire is provided for you to answer.

Study Title: **KNOWLEDGE AND PRACTICES OF HEALTHCARE WORKERS ON SIGNS AND SYMPTOMS OF CHILDHOOD CANCERS IN LEVELS THREE AND FOUR PUBLIC HEALTH FACILITIES IN NAIROBI COUNTY.**

Study background: Cancer is a group of conditions distinguished by unchecked proliferation and dissemination of aberrant cells arising from failure of the mechanisms that regulate normal cell growth and death, causing uncontrollable cell proliferation, degradation of surrounding tissues and dissemination of the disease to other parts of the body

Broad objectives: To determine the level of knowledge of HCWs in levels three and four facilities in Nairobi County on early signs and symptoms of childhood cancers and to determine practices of HCWs in levels three and four facilities in Nairobi County on early signs and symptoms of childhood cancers.

Study Procedures: This study involves getting information from the healthcare workers in level 3 and 4 facilities in Nairobi County about their understanding of general knowledge of childhood cancer and its signs and symptoms as well as practice of cancer management when faced with children with the signs and symptoms of childhood cancer, by use of **questionnaires** and key informant interviews. The questionnaires shall contain questions to be answered by the participants in an unrestricted amount of time without referring to any educational material.

Information will also be sought by **interviewing selected key informants** i.e., in-charges of facilities and consultants. They will be asked questions pertaining to their facilities and the personnel in their facilities with regards to childhood cancer. The interviews will be done in a conducive, friendly environment. Notes as well as audio recording will be done by the interviewer

during the interview with no personal identifiers. This will be done with the consent of the participant.

Voluntariness of participation: Participation is voluntary. We therefore request your permission to involve you in the study.

Benefits of participation: There are no direct benefits for participating in this study.

Risks pf participation: There are no risks for participating in the study.

Rights of Withdrawal: Refusing to participate in this study will have no consequences whatsoever. One may also withdraw from participation in the study at any time they wish with no consequences borne.

Confidentiality: No personal identifiers will be used. Your identity will remain absolutely confidential. All answers obtained will be considered privileged. These will be documented and analyzed anonymously. The researchers aim to publish this paper purely for academic and scientific purposes.

If you have any questions which you feel the investigator explaining to you has not handled or you would want another opinion, feel free to contact the Principal Investigator, Dr. Purity Nyaguthii Muhoro on 0726671571 or the lead supervisor, Dr. Boniface Osano on 0722646720.

For more information, you may also contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee, on 2726300 Ext. 44102, email uonknh_erc@uonbi.ac.ke.

I have understood the explanation given to me about this study and hereby give consent to take part in it.

Name of Participant: ……

Signature……..... Date …….

Name of investigator.....

Signature..... Date.....

10.3 APPENDIX 3: QUESTIONNAIRE

10.3.1. BACKGROUND INFORMATION

1. Study number……...

2. Date of interview……..

3. Facility Name and Type…….

4. Designation:

a) Nursing Officer [ ] b) Clinical Officer [ ] c) Medical Officer [ ] d) Other [ ] Specify _____

5. Age (in years) ……..

6. Sex:

a) Male [ ] b) Female [ ]

7. Length of practice (in years) ……

8. Length of time (in years) since graduation from college/university basic degree/course……

9. Department (current)

a) Pediatrics [ ] b) Internal Medicine [ ] c) Outpatient Department [ ] d) Others (Specify]……

10. Have you undergone any childhood cancer trainings since you graduated from medical/nursing school basic course?

a) Yes [ ] b) No [ ] If No, proceed to part II

11. If yes to question 10 above, how **LONG AGO** was_ your last training? (TICK ONLY ONE THAT APPLIES)

a) Less than 1 year ago [ ] b) 1-5 years ago [ ] c) 5-10 years ago [ ] d) Over 10 years ago [ ]

12. If yes to question 10 above, how many childhood cancer trainings have you attended in the last 5 years? (TICK ONLY ONE THAT APPLIES)

a) 1-2 [ ] b) 2-5 [ ] c) More than 5 [ ]

10.3.2. CHILDHOOD CANCER KNOWLEDGE

1. What is childhood cancer? (TICK ONE CORRECT ANSWER)

a) A group of diseases characterized by growth and spread of normal cells [ ]

b) A group of disease characterized by uncontrolled growth and spread of abnormal cells [ ]

c) A childhood disease of infection [ ]

d) A childhood autoimmune disease [ ]

2. What is the most common etiology of childhood malignancy? (TICK ONE CORRECT ANSWER)

a) Genetic predisposition [ ]

b) Radiation exposure [ ]

c) Viral infection [ ]

d) Unknown [ ]

3. What are the risk factors of childhood cancer? (TICK ALL THAT APPLY) a) I don't know [ ]

b) Infections e.g., EBV [ ]

c) Inheritance/Genetics [ ]

d) Radiation [ ]

e) Living in cities [ ]

f) Treatment with chemotherapy and radiation for prior cancer episode [ ]

g) Unhealthy lifestyle [ ]

h) Chromosomal abnormalities , Down's Syndrome [ ]

4. What type of childhood cancer do you know? (TICK ALL THAT APPLY)

a) Brain tumours [ ]

b) Hepatoblastoma [ ]

c) Nephroblastoma [ ]

d) Colon cancer [ ]

e) Hodgkin's lymphoma [ ]

f) Non-Hodgkin's lymphoma [ ]

g) Osteosarcoma [ ]

h) Oesophageal cancer [ ]

i) Neuroblastoma [ ]

j) Leukaemia [ ]

k) Rhabdomyosarcoma [ ]

l) Prostate cancer [ ]

m) Kaposi sarcoma [ ]

n) Gastric cancer [ ]

o) Retinoblastoma [ ]

5. What is the most common cancer of infancy? (TICK ONE CORRECT ANSWER)

a) Retinoblastoma [ ]

b) Nephroblastoma [ ]

c) Neuroblastoma [ ]

d) Leukaemia [ ]

e) Lymphoma [ ]

6. What is the association between childhood cancer HIV/AIDS? (TICK ALL THAT APPLY)

a) HIV decreases chances of developing childhood cancer [ ]

b) HIV increases chances of developing childhood cancer [ ]

c) HIV has no impact on development of childhood cancer [ ]

7. In general, how do various types of childhood cancer present? (TICK ALL THAT APPLY)

i) Adenopathy [ ]

ii) Headache [ ]

iii) Pallor [ ]

iv) Nystagmus [ ]

v) Prolonged/Unexplained fever [ ]

vi) Anorexia/Weight loss [ ]

vii) Change in gait [ ]

viii) Easy bruising [ ]

ix) Hypertension [ ]

x) Malaise/Fatigue [ ]

xi) Change in bowel habits [ ]

xii) Drenching night sweats [ ]

xiii)Haematuria [ ]

xiv) Hepatosplenomegaly [ ]

xv) Diplopia [ ]

xvi) Unexplained bleeding [ ]

xvii) Growth failure [ ]

xviii) Swellings/masses [ ]

xix) New squint [ ]

xx) Change in behavior [ ]

xxi) Abdominal distention [ ]

xxii) Hemiplegia [ ]

xxiii) Proptosis [ ]

xxiv) Vomiting [ ]

xxv) Seizures [ ]

xxvi) Bone pain [ ]

xxvii) Leukocoria [ ]

xxviii) Enlarging head [ ]

xxix) Joint pain [ ]

8. What are the clinical presentations of lymphoma (NHL and HL)? (LIST)

9. What are the clinical presentations of retinoblastoma? (LIST)

10. What are the clinical presentations of acute leukaemia (ALL and AML)? (LIST)

11. What are the clinical presentations of Wilm's tumour? (LIST)

12. What are the clinical presentations of CNS malignancies? (LIST)

13. A child with bimanually palpable, ballotable abdominal mass, haematuria and hypertension should be suspected to have (TICK ONE CORRECT ANSWER)

a) Hepatoblastoma [ ]

b) Lymphoma [ ]

c) Nephroblastoma [ ]

d) Rhabdomyosarcoma [ ]

e) Cancer of the bladder [ ]

14. Which is the earliest manifestation of retinoblastoma in children? (TICK ONE CORRECT ANSWER)

a) Proptosis [ ]

b) Red eye reflex [ ]

c) Eye discharge [ ]

d) White eye reflex [ ]

e) Squint [ ]

10.3.3. CHILDHOOD CANCER PRACTICES

In this section, please indicate the actual practice and not the ideal/recommended.

1. In your practice since graduation, have you participated in the management of a child with cancer? (*Management in this context entails participation in; cancer diagnosis, treatment, counseling and referral*) [TICK WHERE APPLICABLE]

a) Yes [ ]

b) No [ ] Proceed to question 3.

2. In which of the following aspects of management of childhood cancer have you participated in? (TICK ALL THAT APPLY)

a) Diagnosis [ ]

b) Treatment [ ]

c) Counseling [ ]

d) Referral [ ]

3. In your practice, have you encountered a child with an abdominal mass?

- Yes
- No

If yes, what did you do? (TICK ALL THAT APPLY) If no, skip to question 4. a)

Abdominal x-ray [ ]

b) Abdominal U/S scan [ ]

c) Abdominal CT scan [ ]

d) Refer to a surgeon [ ]

e) Others [ ]

(Specify)……

4. In your practice, have you encountered a child with pallor?

- Yes
- No

If yes, what did you do? (TICK ALL THAT APPLY) If no, skip to question 5.

a) Do a full haemogram [ ]

b) Give haematenics [ ]

c) Give blood transfusion [ ]

d) Refer [ ]

e) Others [ ]

(Specify)……

5. In your practice, have you encountered a child with unexplained, prolonged, fever?

- Yes
- No

If yes, what did you do? (TICK ALL THAT APPLY) If no, skip to question 6.

a) Give antibiotics

b) Give antipyretics

c) Do a full haemogram

d) Do a septic screen

e) Refer

f) Others [ ]

(Specify)……

6. In your practice, have you encountered a child with anorexia/unexplained weight loss?

- Yes
- No

If yes, what did you do? (TICK ALL THAT APPLY) If no, skip to question 7.

a) Give appetite boosters

b) Check for infection

c) Advice mother on proper nutrition

d) Refer to nutritionist

e) Refer to pediatrician

f) Others [ ]

(Specify)……

7. In your practice, have you encountered a child with drenching night sweats and enlarged lymph nodes?

- Yes
- No

If yes, what did you do? (TICK ALL THAT APPLY) If no, skip to question 8.

a) Investigate and treat for Tuberculosis

b) Do a lymph node biopsy

c) Refer

f) Others [ ]

(Specify)……

8. In the diagnosis of childhood cancer which diagnostic techniques have you participated in? (TICK ALL THAT APPLY)

a) Biopsy for Histology [ ]

b) Bone Marrow Aspirate [ ]

c) FNA for cytology [ ]

d) History and physical exam [ ]

e) Imaging e.g., X-ray, Ultrasound CT scans, MRIs [ ] 8)

f) Lab investigations e.g., Full haemogram with peripheral blood film [ ] g) Others [ ]

(Specify)……

h) I have never diagnosed/helped in diagnosis of any childhood cancer [ ]

9. Do you counsel children or parents of children diagnosed/suspected with cancer on the available modes of treatment? (TICK WHERE APPLICABLE)

a). Yes [ ]

b) No [ ]

c) I have never encountered children diagnosed with cancer in my practice [ ]

10. Do you counsel the parents on the prognosis of the cancers affecting their children? (TICK WHERE APPLICABLE)

a) Yes [ ]

b) No [ ]

c) I have never encountered children diagnosed with cancer in my practice [ ]

11. Have you ever treated/participated in the treatment of a child with cancer? (TICK WHERE APPLICABLE)

a) Yes [ ]

b) No [ ] Proceed to question 13

12. If yes to question 11 above, how did you participate? (TICK ALL THAT APPLY)

a) Administering chemotherapy [ ]

b) Administering immunotherapy [ ]

c) Administering radiotherapy [ ]

d) Performing/Assisting in surgery [ ]

e) Supportive care [ ]

f) Others [ ]

(Specify)……

13. Have you ever participated in referring a child with suspected/confirmed cancer for further management? (TICK WHERE APPLICABLE)

a) Yes [ ]

b) No [ ] Proceed to question 15

14. If yes to question 13 above, where do you refer them to? (TICK ALL THAT APPLY) a) Level 4 hospital [ ]

b) Kenyatta National Hospital [ ]

c) Private Facility [ ]

d) Others [ ]

Specify……1

5. Is it important to refer a child suspected or diagnosed with cancer immediately? (TICK WHERE APPLICABLE)

a) Yes [ ]

b) No [ ]

16. Do you encounter any challenges referring children with suspected/confirmed cancer? (TICK WHERE APPLICABLE)

a) Yes [ ]

b) No [ ] Proceed to question 18

c) I have never encountered children diagnosed with cancer in my practice [ ] Proceed to question 18

17. If yes to question 16 above, which ones? (TICK ALL THAT APPLY)

a) Lack of Transport [ ]

b) Unwillingness of the parents/guardians to refer the patient [ ]

c) Communication problems with the receiving facility [ ]

d) Lack of proper referral structures [ ]

e) Others [ ]

(Specify)……

18. Do you counsel the guardian/parent of a child with cancer on the importance of timely referral of their children to cancer treatment centers? (TICK WHERE APPLICABLE) a) Yes [ ]

b) No [ ]

19. Do you advice your patients to get NHIF? (TICK WHERE APPLICABLE)

1. Yes [ ]

2. No [ ]

10.4 APPENDIX 4: KEY INFORMANT INTERVIEW

The interviewer will ask the following questions as a guide and give the participant time to respond to each. Audio recording will be done during the interview.

1. Literature has shown that healthcare system delays contribute more to late diagnosis and consequently poor prognosis of childhood cancer than patient/parent delay. In your opinion, why do you think this is so?
2.

i) For level 3 facilities: In your experience, what are the challenges you face in identifying suspected childhood cancer in your facility?

ii) For level 4 facilities: In your experience, what are the challenges you face in diagnosis of childhood cancer in your facility?

3. What do you think leads to late diagnosis of childhood cancers?
4. In your opinion, what can be done to improve the healthcare system delays in diagnosis of childhood cancer?

10.5 APPENDIX 5: STUDY WORK PLAN AND BUDGET

10.5.1 Study Timeline

	2020 Oct	Nov	Dec	Jan	2021 Feb	Mar	Apr	May	Jun
Finalize research proposal and submit for clearance from ERC	x								
(After obtaining clearance from ERC :) Inform and get consent and authorization from the department of health Nairobi County and relevant Medical Superintendents		x							
Prepare research tools including printing questionnaires		x							
Identify, recruit and train research assistants		x	x						
Pre-test study and finalize procedures/tools			x						
Collect data			x	x	x				
Data editing, coding and entry into computer			x	x	x				
Data analysis						x			
Report writing						x			
Disseminate and discuss research findings and recommendations with health staff and community members							x		
Prepare final report and submit to concerned institution/s							x		
Disseminate and discuss research findings with policy makers/managers/others								x	
Draft preliminary plan of action								x	

Hold meetings with policy makers/managers to discuss plan of action for implementing recommendations									x
Follow up on implementation of action plan									x →»

10.5.2 Budget

Personnel/Item	**Rate (Ksh)**	**Total (Ksh)**
Research assistants (4)	10,000	40,000
Statistician (1)	25,000	25,000
Transport/fuel	15,000	15,000
Stationary (Printing, Photocopy, etc.)	15,000	15,000
Miscellaneous	5,000	5,000
Grand total		**100,000**