ASSESSING PALLIATIVE CARE NEEDS IN CHILDREN WITH HIV AND CANCER

The case of Children attending University teaching hospital in Zambia

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DECLARATION

I, **Wilbroad Mutale**, hereby declare that the work on which this dissertation/ thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABSTRACT

Background

WHO has been advocating for provision of palliative care for all who need it according to needs and context. Though significant advances have been achieved in providing palliative care for adults in Sub Saharan Africa, very little progress has been made in providing paediatric palliative care. Coverage of paediatric palliative care services have remained low and there is lack of evidence on child specific palliative care needs and tools for assessing these needs. This study tested applicability of some tools for assessing palliative needs in children in the Zambian context and reports palliative care needs of children and their families attending the University Teaching Hospital (UTH) in Lusaka, Zambia

Methodology:

This was a mixed study with quantitative and qualitative components. The quantitative component assessed and applied 2 new research tools for assessing palliative care needs in children attending University teaching hospital in Lusaka, Zambia. The tools assessed included the Needs Evaluations questionnaire (NEQ) and the paedsQL4 questionnaire. Cronbach‘s alpha was used to determine reliability while factor analysis was used to identify relevant factors. Focus group discussions were conducted with selected group of parents/legal guardians of children. In-depth interviews were conducted with key informants. All participants were purposely selected to take part in the study and were informed about the voluntary nature of the study.

Results:

The NEQ and the paedsQL4 questionnaires were both found to be reliable for assessing palliative care needs for children in the Zambian context (Cronbach‘s alpha >0.8). Generally there were very high need gaps across all hospital wards with 15/23 items having need gap of >50%. Overall the largest need gap was in the information domain. The HIV ward had least need gap with only 8/23 items having a need gap of > 50%.

Results from the paedsQL4 showed that there were significant mean differences across the three categories of patients in all domains of functioning with oncology patients

performing worst. In physical functioning domain, the items showed that 6/7 items had significant mean differences ($p<0.05$).Confirmatory factors analysis showed that 2 items were loading highly on the physical functioning factor. These were running and participating in sports (0.896).In the emotional functioning domain, 2 items loaded highly on factor analysis, feeling sad (0.842 and angry (0.666).In the social functioning domain, highest loading were in 2 items, both related to making friends. In the school domain missing school to go to hospital loaded highly on factor analysis (0.842) followed by difficulty paying attention in class (0.716)

Qualitative results supported findings from quantitative data. Several needs were highlighted by the parents/guardians and health workers. The major family needs focused on economic/financial and bereavement support. Most families were referred to the UTH from very far off places without any form of support. In line with quantitative findings, there was high demand for information for families which health workers did not adequately provide. One major barrier identified to provision of palliative care was poor coordination of services with most patients missing out on services which were already available. While social workers were available, poor funding negatively affected this service. There were very few trained health workers in palliative care. Pain management remained poor with many clinicians still not comfortable to prescribe stronger analgesia such as morphine for severe pain.

Conclusion:

This study applied two quantitative tools for assessing palliative care needs in Children. The results showed that the tools were fairly reliable and applicable in the Zambian context. The findings indicate huge needs gap for child palliative care services in Zambia. The major family needs were economic and bereavement support. There was high demand for information for families which health workers did not adequately provide.

Pain control remained sub-optimal especially for children with cancer. One major barrier identified to provision of palliative care was poor coordination of services.

ACRONYMS:

AIDS Acquired Immune Deficiency Syndrome
APCA African Palliative Care Association
ART Antiretroviral Therapy
ARVs Antiretrovirals
FGD Focus Group Discussion
IDI In-depth Interview
ICHC Integrated Community-Based Home Care
ICPCN International Children‘s Palliative Care Network
HIV Human Immunodeficiency Virus
MOH Ministry of Health
NEQ Needs Evaluation Questionnaire
PAEDSQL Paediatric Quality of Life inventory
PEPFAR: President's Emergency Plan for AIDS Relief
PCAZ Palliative Care Alliance of Zambia
PLWHA People Living with HIV/AIDS
PMTCT Prevention of Mother to Child Transmission
PNPC Problems and Needs in Palliative Care questionnaire .
UN United Nations
UNICEF United Nations Children's Fund
UTH University Teaching hospital
VCT Voluntary Counselling and Testing
WHO World Health Organization

1.0. Introduction

The International Children's Palliative Care Network (ICPCN) has highlighted the need to extend palliative care services for children worldwide[1]. This study aimed to generate evidence on palliative care needs for children and assessed applicability of some tools for assessing these needs for children in the Zambian context.

1.1. What is palliative care

Palliative Care is the care of people who have been diagnosed with a life threatening or chronic illness. It includes the relief of suffering and management of pain and other symptoms. According to World Health Organization (WHO), palliative care should be an integral part of comprehensive care and support given as part of a continuum of care from the time the incurable disease is diagnosed until the end of life[2]. Palliative care acts neither to hasten nor postpone death, but integrates the psychological and spiritual aspects of patient care and offers a support system to help patients live as actively as possible until death. In addition, it provides a support system to help the family cope during the patient's illness and through their own bereavement" [2]. In order to ensure adequate population coverage it is important that palliative care is provided in health institutions as well as home and community-based organizations [3, 4]

Palliative Care has also been described as a holistic approach to care that is advocated to meet the needs of the whole person and places patients and their families within a model of care that meets their physical, social, psychological and spiritual needs. It involves looking at the patient as a whole i.e. taking into account all the different aspects of the patient's life and context of the illness[5].

Holistic approach model of palliative care:

1.2. What constitutes Palliative Care

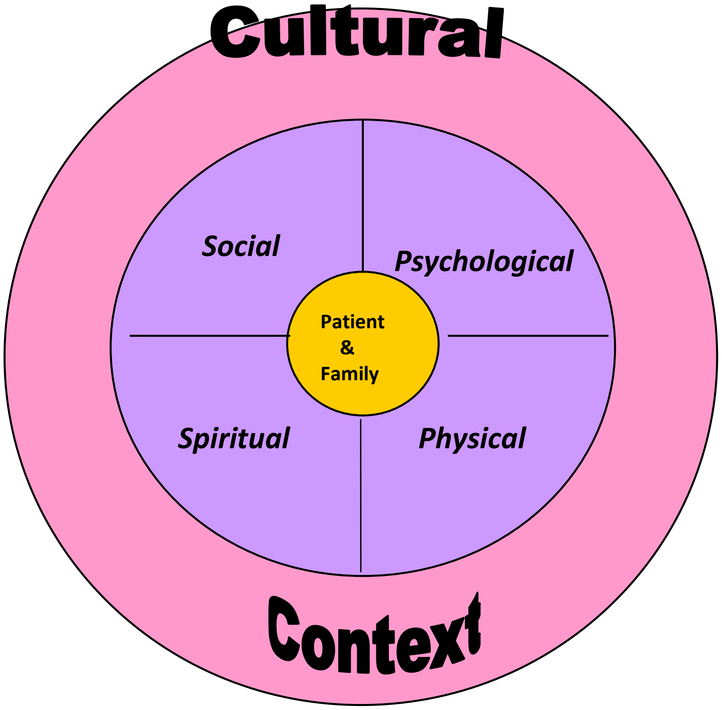

Diagram: Colette Cunningham, CRS-Zambia

There are two essential components to Palliative Care 1) Pain and symptom control (control of distressing symptoms, including the administration of oral morphine for moderate-to-severe pain using the WHO analgesic ladder) and 2) Supportive care (the psychological, social, spiritual, and cultural needs of the patient and family, including bereavement care) [5].

In Africa, Palliative Care is looked at from the continent‘s diverse needs, especially in Sub-Saharan Africa, where components of Palliative Care include: practical care, pain and symptom management, emotional support, clean water, income generation, nutritional support, shelter and spiritual care. These make a difference in improving the quality of life for thousands suffering from life-threatening illnesses such as HIV and Cancer [4, 6-8]

1.3. Palliative needs in HIV

HIV remains a major cause of mortality and morbidity in Sub Saharan Africa with many people requiring palliative care at various stages of the illness. WHO advocates palliative care as an essential component of HIV care from the point of diagnosis to the end of life and into bereavement [2]. This means providing palliative care alongside ART. There is improved availability of ART but there is still a challenge in providing appropriate palliaitve care. A study done in South Africa found that there were limited resources dedicated to palliative care for AIDS patients, ineffective control of pain, models of care heavily relied on volunteers and that stigma remained high [9].

The WHO states that ―Palliative Care for children represents a special, albeit closely related field to adult Palliative Care", but children have different needs to adults. WHO defines Palliative Care for children with chronic, terminal or life-threatening illness as ―The active total care of the child's body, mind and spirit and also involves giving support to the family, begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. This requires health providers to evaluate and alleviate a child's physical, psychological, and social distress" [5].

1.4. Chronic illness and need for palliative services

Cancer is a major cause of morbidity and mortality world-wide. The number of people dying of cancer each year is about 6.7 million. Millions more are being diagnosed with cancer in both developed and developing countries [10]. Being diagnosed with cancer is an overwhelming experience not only for the patient but for family and loved ones. There are stages in which the patient and family go through from the time of diagnosis to the time that the patient dies. At each stage, the patient and family require support through their difficult times[11]. The suffering that the families undergo is multidimensional, hence requiring a multi-disciplinary approach in alleviating it. A holistic approach in caring for a terminally ill patient at the end of life is an integral part of good palliative care [12, 13]. Understanding and responding to family dynamics is a key component in the provision of comprehensive care for persons with progressive illness. Patients and families value being involved in decision making especially when death is imminent [14].The family‘s role with respect to the patient is especially important in the terminal stage of their illness, since this is the last opportunity for them to help the patient [15, 16].

1.5. Palliative care for children

A recent evaluation of the status of palliative care in Sub-Saharan African revealed that children and their families in sub-Saharan Africa facing progressive, incurable and life-limiting disease have lacked the access to evidence-based palliative care that is available for adults which is also limited. In addition, there is a lack of literature on childhood palliative care needs and outcomes in sub-Saharan Africa [17].

Paediatric palliative care may be needed for a wide range of diseases, which differ from adult diseases and many of which are rare and familial. The diagnosis influences the type of care that a child and family will need and four broad groups have been identified. Palliative care may be needed from infancy and for many years for some children, while others may not need it until they are older and only for a short time. Also the transition between aggressive treatments and palliative care with a goal of quality of life may not be clear—both approaches may be needed in conjunction, each becoming dominant at different stages, as described by the WHO definition of palliative care [2]. HIV falls in the group of diseases where intensified treatment with antiretroviral drugs can prolong life and relieve much suffering for the family and the patient [18, 19].

Group Examples of chronic illness that require palliative care in children	
Diseases for which curative treatment may be feasible but may fail	*Cancer*
Diseases in which premature death is anticipated but intensive treatment may prolong good quality life	*Cystic fibrosis, HIV infection and AIDS**
Progressive diseases for which treatment is exclusively palliative and may extend over many years	*Batten disease* *Mucopolysaccharidoses*
Conditions with severe neurological disability that, although not progressive, lead to vulnerability and complications likely to cause premature death	*Severe cerebral palsy*
Adapted from Goldman A, 1998	

2.0. Literature review:

The literature review has been organised as follows: Section 2.1 gives a summary of the approach to the literature review. Section 2.2 provides an overview of models of palliative care describing the different models including advantages and limitations. Section 2.3 extends the discussion on palliative models, describing how they apply in the African context in view of the HIV pandemic and special palliative care needs associated. The section concludes that there are many unmet needs for palliative care for patients with HIV. It was noted that most studies cited had limitations in terms of scope and patient populations studied so they could not be generalizable to the whole HIV population. Section 2.4 narrows down to palliative care needs for children in Africa, highlighting the gaps in the services for children. The literature review highlighted the lack of information on palliative care needs for children in Africa and most available evidence was based mainly on aggregate population level data. Section 2.5 takes the literature further, looking at how the needs for palliative care can be assessed. The literature review demonstrated the bias of needs assessment towards high income countries with very few palliative care needs studies conducted in Sub-Saharan Africa. Sub-section 2.5.1 explores the tools which have been used to assess palliative care needs for adult population while sub -section 2.5.2 reviews literature in relation to tools which have been used to assess palliative care needs in the paediatric population. It was clear from the literature that while a number of tools exist for adults and children, their use has been limited to high income settings requiring further adaptation and validation in the African context.

2.1. Approach to literature review

Both grey and published literature were reviewed. We first used google to gather general information. This provided information mainly on reports, relevant websites and other grey literature. We then narrowed our search to specialised search engines: google scholar, PubMed, Scopus, Web of science and Cochrane library. Specific journals in palliative care were also reviewed. The main search terms included: Palliative care, Model(s) of Palliative care, Palliative care AND children, Palliative care AND Africa (Sub-Saharan Africa), Palliative care AND HIV/AIDS, Palliative care needs, Palliative care AND needs assessment (tools). Palliative care AND needs assessment AND Children AND Paediatrics.2.2. Models of Palliative care

Palliative care in Africa is in its relative infancy, with dedicated financial support extremely limited. Powell et al, conducted a study to identify palliative care needs in Africa.The authors collected information from local stakeholders and researchers.They reported two main topics needing prioritisation. These were: 1) research on palliative care needs for families and patients and 2) integration of palliative care into the health system [20]. This finding emphasised the fact that before investments are put to support palliative care, it is crucial to establish the most urgent needs especially in the African setting were resources are limited.

There are two main models of deliverying palliative care described by Clark et al These are facility-based (hospital or hospice) and community based model) [21]. In Africa both models are being used though hospital based palliative care is the least provided [21]. A study conducted in Malawi in hospital settingsby Tapsfied et al., looked at the demographic characteristics of the patients accessing palliative care showed that majority were young aged group and HIV positive (54%). Malignancy made less than 10% of clients. Pain was the most commonly reported symptom (74%) [22].

Hospice palliative care is a common model of palliative care delivery especially in high income countries. Clark et al conducted a study in 2007 to review the status of palliative care service provision in hospices across the continent focusing on existing services and the experience of those working in selected settings. They conducted a multi-method study covering 47 countries in the Sub Saharan region.They found that 21 countries had no identified palliative care services and of the 11 countries with some form of palliative care, the majority were being supported by external donors with limited intergration with the existing health system. Overall, they found palliative services provided limited coverage for care in Africa. The major challenges in delivery of palliative care were availability of opioids and lack of trained health workers and financial resources [21]. This study was followed by a review in 2011 published as the Global Atlas of Palliative Care which showed that Africa was the region with the most improvement in palliative care development between 2006 and 2011, although there is still a lot of work to be done[23].

Downing and colleagues conducted an evalution of a community based model of delivering palliative care. They found that a model which was closely alligned to the WHO recommendation was emerging.They referred to this model as the —Nnkya” model.They concluded that this model appeared to be suitable for African settings context especially rural areas [24].The model was particularly suitable for providing palliative care in the context of HIV and had potential to increase coverage. However, they also acknowledged that more work is still required to show how this model could be intergrated into the existing public health system [24, 25].

In South Africa, the South Coast Hospice developed a model described by Defilippi & Cameron which relied not only on the hospice resources but included all relevant community service providers. This model which has come to be known as the Integrated Community-Based Home Care (ICHC) model and is implemented in South African hospices has a strong focus on linkages across the continuum of care. It allows for referral between all partners as trust is built and it develops palliative care capacity in all partners. It ensures that community caregivers are trained, and then supervised and supported [26].

2.3. Palliative care in the context of HIV

A study by Harding et al found that patients with HIV in Sub Saharan Africa had several physical and psychological problems.The most common was pain and worry about the future. In multivariate analyses, being cared for at home was associated with poorer physical/psychological factor score (B=-0.192, 95% CI -2.566 -0.464, p=0.005), while being on ART was associated with better factor score (B=0.187, 95% CI=0.424 23.80, p=0.005).They concluded that those receiving care at home were poorly served due to limited resources [27]. The major limitation of this study was that it presented quantitative results yet some of the components of palliative care are better assessed using qualitative methods.

A study conducted in Rwanda by Uwimana et al investigated the met and unmet palliative care needs of PLWHA in selected areas in Rwanda. The study sample included 306 participants: PLWHA, health care professionals and coordinators of HIV/AIDS units. The most common perceived palliative care needs of PLWHA were medical needs, psychosocial needs and the need for financial assistance (77%); home-based care (47%); nutritional support (44%); pain relief and management of other symptoms (43%). Most PLWHA indicated these palliative care needs were unmet, in particular the needs for pain relief, symptom management, financial assistance and nutritional support [8]. Though the study collected information from patients' perspective, it highlighted critical gaps in services which were provided for most PLWHA in Sub-Saharan Africa.

In Tanzania, Collins et al, in 2007, measured the prevalence of multidimensional palliative care needs of adult patients with HIV disease. Palliative care intervention was indicated for 378 (51.7%) patients. Among those 434 patients using ART, 230 (52.9%) were indicated as having palliative care needs. It was concluded that palliative care remained an essential element in patient management even in the presence of ARV treatment [6].

Jameson investigated the palliative care needs of patients with stage 3 and 4 HIV infection in a district hospital of South Africa. Fifty stable patients who were admitted to the medical ward of the hospital with stage 3 and 4 HIV infection were interviewed. 95% of the patients had unresolved medical problems and needed symptom relief. All the patients had some socioeconomic problems and 56% had no income. Poor housing (50%) and no access to electricity (28%), or running water (48%) were also major problems. Lack of transport (96%) and worries about the future of children left behind were concerns of 96% and 72% of respondents respectively. The study did not find psycho-spiritual issues as major problem with 80% having spiritual and family support[28].The limitation of both studies was that they all reported on patients with advanced HIV disease limiting generalisability to others with less advanced disease.

2.4. Children's palliative care

In Sub Saharan Africa, children's palliative care has not developed at the same pace as that of adult palliative care. One of the few studies of children's palliative care described in Africa was by Amery et al in 2009. The researchers conducted a mixed quantitative and qualitative methodology study.They found that following the introduction of childrens' palliative care, there was an increase in the number of referrals, the number of children enrolled on the program and the number of morphine prescriptions.The most valued services were free drugs, food, play, learning and positive staff attitude. It was reported that poor staff attitude, lack of school fees and poor treatment compliance rates were among the issues which negatively affected the program.They also noted that staff of lack confidence and/or competence was a significant barrier to children's palliative care that should be addressed in Africa [29].

A recent study by ICPCN and UNICEF demonstrated a huge gap between need for and provision of specialised palliative care in Sub Saharan Africa. The study showed that the number of children reached with palliative care services in 2012 was 14,501 in South Africa (~5% of specialised need), 545 in Kenya (less than 1% of the specialised need), and 5,438 in Zimbabwe (~5% of specialised need). The major limitation of this study was the reliance on secondary data sources and basing many of the assumptions on data from high income countries which might not be applicable in low income settings.[1]

2.5. Assessing palliative care needs

Caring for patients with life limiting conditions require a thorough understanding of not only the disease but also the personal circumstances of individual patients and their families. According to Stoneberg et al, , finding out appropriate needs for patients and family remain an important first step in providing quality palliative care [30]. Unfortunately many institutions providing palliative care services fail to identfy the needs of the patients and their families.Robbin and Frankel, conducted a review of institutions providng palliative care in the UK showed that half of the institutions had never had any form of needs assessment yet they continued to provide paliative care [31].The results were similar to those reported by Clark et al 10 years earlier which showed very few institutions perfoming needs assessements despite 73% of study participants saying it was an important thing to do [32]

Monterosso and others conducted a study in Australia to look at the palliative care needs showed that parents and guardians needed clear and honest information about their child's condition and prognosis throughout the trajectory of illness. They also wanted access and advice from multidisciplinary health professionals when caring for their child at home. Many families were affected emotionally and financially by the burden of caring for their child with incurable cancer. Families required financial and practical assistance with providing care from their children. Pain management was another important need identified by parents and guardians [33]. This study only looked at guardian perspective and did not include views from affected children.

Another study by Chan et al, aimed to assess palliative care needs for adult patients with terminal cancer found that pain was the most common symptom and was satisfactorily improved in only two-thirds of the patients with one third receiving indequate pain relief. Psychological problems remained a major concern though this was poorly documented in patient‘s files [34]. This study was done in an adult emergency care unit and therefore cannot be generalised to in-patients or paediatric population.

A study done by Ingiln et al, looking at palliative care needs in children found that parents of children with cancer experienced poor coordination and communication in providing palliative care. Families affected expressed the need for psychosocial and bereavement support [35]. This study higlighted the need for clear information sharing with families and adequate pain relief.The study was done in high income setting and some issues raised the need for validation in other settings.

2.5.1. Tools for assessing palliative needs in the adult population

Many scholars have been working to develop and validate tools for assessing palliative care needs which are context specific.

A study by Harding and others aimed to validate a multidimensional scale (the APCA African Palliative Outcome Scale) in a multi-centred international study for assessing needs and outcomes in palliative care. The study was conducted in five African countries. The validation involved 682 patients and 437 family carers. They found low internal consistency in the evaluated items with a Cronbach's Alpha of 0.6. However, they found high intra-class correlation coefficients for all items (0.78-0.89). The tool was easy to use and fast to comprehend by participants [36]. This tool has shown potential for use in Africa and has recently been used in many other settings

Another tool was tested and validated by Richards et al, in the emergency setting.The tool was assessing palliative care symptoms for patients with cancer in the emergency department. It was validated for use to screen for Palliative and End-of-life care. This tool had 120 items. Results showed that the instrument was reliable and valid for screening palliative care needs for patients with cancer in the emergency department with Cronbach‘s coefficient alpha ranging from 0.716 to 0.991[37]. Nonetheless, this tool has not been applied in non-emergency or paediatric population. It therefore requires further validation to ensure it applies in other settings and different patient population

Ewinget al. 2013 developed a tool for assessing palliatve care needs for families and carers. They used this tool in hospice setting in the United Kingdom. They reported that this tool covered domains comprehensively for assessing carer support needs [38]. However, the tool only focused on carer needs and adult population.

Osse et al developed the Problems and Needs in Palliative Care questionnaire (PNPC). It was developed to support the provision of care tailored to the specific demands of patients. Validity and reliabitity was tested on 64 adult patients with metastatic cancer and living at home. Of 140 initial items, reliability analysis supported the proposed dimensions, with Cronbach's alpha coefficient >0.70 for dimensions with > or = 5 items, and alpha >0.65 for the 3- and 4-item dimensions. The authors however reported that the dimensions 'physical symptoms' and 'social issues' lacked coherency with some low item-total correlations [39]. The tool has been limitated to research conditions. It therefore requires further studies to evaluate the applicability in routine clinical settings.

Another tool known as the Needs Evaluation Questionnaire (NEQ) by Bergstraesser et al, has been used to assess palliative care needs. It has been described as a practical and short instrument designed to record hospitalized patients' necessities. The tool was admistered to 600 consecutive hospitalized cancer patients in Italy. Exploratory factor analysis revealed the presence of five factors which related to patients needs.These were informative needs, needs related to assistance/care, relational needs, needs for psychoemotional support and material needs.These needs explained a total of 50.5% of the variance in factor analysis [40]. This tool was mainly applied to an adult population.

2.5.2. Tools for assessing palliative needs in the paediatric population

Ingleton has argued that needs assessment is an important ingrendient in providing quality palliatve care yet it is often neglected or poorly conducted. One reason for this is lack of standard tools to assess palliative care. This lack of tools is even more apparent for tools assessing palliatve care needs in children [41].

Bergstraesser et al recently reported about a tool that has potential for assessing palliative care needs in children. They focused their work in high income countries. The results showed five domains relevant to identifying children with life-limiting diseases, who could benefit from palliative care.These were 1) trajectory of disease and impact on daily activities of the child; 2) expected outcome of disease-directed treatment and burden of treatment; 3) symptom and problem burden; 4) preferences of patient, parents or healthcare professional; and 5) estimated life expectancy [42]. This tool still remains preliminary and further research is required to validate the identified domains.

The Paediatric Quality of Life Inventory (Paeds4QL, Children's Hospital and Health Center, San Diego, California) is a modular instrument for measuring health-related quality of life (HRQOL) in children and adolescents ages 2 to 18. The Paeds4QL generic core scales are multidimensional child self-report and parent proxy-report scales developed as the generic core measure to be integrated with the Paeds4QL Disease-Specific Modules [43]. This tool has been reported to be valid for measuring palliative care needs in children with cancer and diabetes. According to one study which validated the Paeds4QL tool, it had internal consistency and reliability for the total Scale Score (alpha = 0.88 child, 0.90 parent report). The Paeds4QL distinguished between healthy children and paediatric patients with acute or chronic health conditions [44]. This tool is easy to use and has been replicated in other studies, nonetheless, this tool has never been used in the Sub Saharan African context.

The African Palliative Care Association (APCA) developed a paediatric patient-level outcome measure – the APCA African Children‘s Palliative Outcome Scale (POS) and some guidance on how to use. The APCA African Children‘s POS was developed in a consultative process that included a multi-disciplinary, multi-national group of experts in the field of children‘s palliative care in Africa. As a first stage in the process, a literature search was undertaken to review available outcome measurements applicable to children. The literature review was followed by a workshop held in 2009 in Kampala, Uganda, which brought together experts from across sub- Saharan Africa to discuss the feedback from the literature review and develop an initial draft for the first phase piloting. At the Uganda meeting, an initial draft version of the APCA African Children‘s POS was developed, It had two versions - one for ‗verbal‘ children and one for ‗non-verbal children‘. The first stage of piloting was conducted between in Kenya, South Africa and Uganda. This was followed by a meeting in Nairobi, Kenya to review the findings of the first stage pilot. The tool showed sensitivity to change over time in multiple domains among the target population. The expert panel recommended combining the two versions into a single tool to avoid confusion which was noted during the pilot. The second phase pilot was conducted in 2011 in four countries: Kenya, South Africa, Uganda and Zimbabwe. Following the second phase piloting, the results were circulated to a group of experts from Kenya, South Africa, Uganda, the United Kingdom and Zimbabwe. Further modifications were made to the tool in preparation for its final validation. The validation phase was undertaken in three different countries: Kenya, South Africa and Uganda. The results have not yet been published but it has been noted that this tool will be useful in improve palliative care service on Africa. [45]

3.0. Study rationale

Zambia is among the countries worst affected by the HIV epidemic. In relation to the paediatric context, over 95,000 children were reported by UNICEF (2010) to be infected with HIV mainly through mother to child transmission [46]. In addition, Zambia has many childhood malignances, many of which are referred to the hospital late and some remain undiagnosed due to lack of health services especially in rural areas. While ARVs and cancer treatment are available in urban areas, this is not the case in rural areas. With an increase in the number of children on ART and cancer treatment, there is a need to establish palliative care needs in these children in Zambia in order to provide holistic care for affected children and their families and document this evidence to guide future research in this area.

Aim and Objectives

4.0. AIM:

To determine palliative care needs of children and their families attending University teaching hospital in Lusaka, Zambia

4.1. Objectives:

4.1.1. To describe the socio-demographic characteristics of children with chronic illnesses at university teaching hospital
4.1.2. To evaluate tools for assessing palliative care in children.
4.1.3. To determine palliative care needs in children with HIV at University teaching hospital as described by parents/legal guardians and hospital staff
4.1.4. To establish palliative care needs of children with Cancers at University Teaching hospital (UTH) as described by parents/legal guardians and hospital staff

5.0. Methodology

5.1. Study design

This was a cross-sectional mixed qualitative and quantitative study. .

5.2. Study site

The study was conducted at the University teaching hospital in Lusaka which is the main referral hospital in Zambia.

5.3. Target population

There were two groups of target populations

i) Parents/legal guardians of HIV infected children or children with other chronic diseases attending ART or Oncology clinics, OPD or admitted to the general ward.
ii) Paediatric staff: The head of Department for paediatrics and Child health, head of clinical care (paediatrics), consultants in-charge of general paediatrics, oncology and paediatrics ART. The nurse in-charge of

oncology and ART Units, doctors, nurses and social workers, chaplaincy working in the general ward, oncology unit and ART clinic

5.4. Eligibility criteria

i) Parents/legal guardians of children under the age of 16 years with chronic illness attending the University teaching hospital in Lusaka.

ii) All paediatric staff

5.5. Sample size calculations for quantitative study

The total sample size of parents or guardians of children living with cancer and children living with HIV was 100. The sample size calculation was based on the following assumptions: Power of 80% and confidence level of 95%. The number of children with cancer was 300. The number of children on ART was 500 in 2012. Assuming the proportion of those with palliative care needs to be 50% and worst expected to be 40% in each group. Sample size was calculated using Epi info Version 7(www.cdc.gov/epiinfo) based on the following Formula:

$n = (Z^2 X P(1 – P))/e^2$

n=Sample size

Where Z = value from standard normal distribution corresponding to desired confidence level (Z=1.96 for 95% CI)

P is expected true proportion

e is desired precision (half desired CI width).

5.6. Sampling for qualitative study

Focus group discussion:

Focus group discussions were conducted with selected groups of parents/legal guardians of children. Participants were purposely selected to take part in the study if they met the eligibility criteria and had consented to take part in the study. A total of 9 focus group discussions were conducted as follows:

2 with parents/legal guardians/in oncology ward

2 with parents/legal guardians in HIV clinic

2 with legal guardians in the general paediatrics ward

1 with health workers in oncology unit.

1 with health workers in HIV clinic

1 with health workers in the general paediatric ward

5.7. Data collection

. ***A) Quantitative study tools and the target respondents***

- **PaedsQL4** (*Annex 2):* Is a standard rapid and validated tool for paediatric needs assessment from a point of legal guardians.
- **Needs Evaluation Questionnaire** *(NEQ: Annex 7)***:** Is a standard and validated rapid tool for needs as expressed by legal guardians on behalf of their children.

  These tools were used to collect information from parents and legal guardians of children with cancer or HIV or general paediatric conditions.

B) Qualitative study tools and target respondents

Focus group discussions (FGDs):

Focus group discussions were held with parents/ guardians and Health workers separately. The tools used to collect information were developed based on literature and consultation with colleagues who had palliative care experience.

- **FGD guide for parents/legal guardians** ***(****Annex 4****):*** This tool was used to collect information from legal guardians. FGD were held in Oncology unit, HIV clinic and general paediatric ward.
- **FGD guide for health workers** ***(****Annex 5****):*** This tool was used to collect information from Health workers. Health workers included nurses, social workers, doctors and any other health worker supporting working in oncology, HIV clinic and general Paediatrics ward.
- **In-depth interview guide for Health workers** *(Annex 3):* This tool was used to collect information from key informants who included the clinical care specialist, the priest, social worker and nursing sisters and consultants.

5.8. Data collection process

All eligible participants were approached by the research team. The voluntary nature of the study was emphasised. They were assured of confidentiality. If they agreed to take part a consent form was given to them to read in the presence of the research team. Children were given an opportunity to know about the purpose of the study and why their parents/legal guardians had been approached to take part. The age of the child was taken into consideration when providing information. *(See Annex 1 & 8)* Consent was obtained for the quantitative survey, for FGD and for individual interviews.

In this study a distress protocol was developed to take care of parents/legal guardians who become distressed during data collection process. The distress protocol explained how to handle participants who became distressed during interviews. If at any point during the interview any participant was noticed to be distressed, the researcher was to stop the interview or focus group discussion. The researcher was to establish the most appropriate action whether to take a short break to allow the participant to settle back. If necessary the researcher was to help the participant to leave the interview. All research assistants were trained on how and when to apply the distress protocol *(See annex 6)*

5.9. Training of research assistants:

Research assistants were separated into groups. One team collected quantitative data from respondents. The second team helped conduct qualitative interviews. Training was conducted for each group separately. The quantitative research assistants were trained for five days. They were introduced to the study and the study tools and oriented in good clinical practice principles. After three days of training in data collection tools, field pre-testing of the tools was done on similar respondents to the target audience.The last day of training was used to share feedback from pre-testing and tools were reviewed taking into account the pre-test experience.

Two research assistants experienced in qualitative methods were recruited to support the principal investigator in data collection. They were trained for 5 days. They were firstly introduced to the study and the interview guides. They were given an opportunity to pre-test the study guides and tape recording of interviews. All qualitative data from in-depth interviews and Focus group discussions were tape recorded and transcribed by the principal investigator with support from the two trained research assistants.

5.10. Confidentiality

Confidentiality was maintained throughout the data collection process. The name of the individual participants were recorded only on the consent form. Each participant was given a unique ID number. Signed consent forms were locked away in a cabinet accessible only to the study Principal investigator. All electronic data were held under password protected data files.

Organisation of FDGs

A quite counselling room was used to conduct all FGDs. Appointments were made a day before the interview and convenient time was agreed. The principal Investigator led all the discussions. All the participants were informed that information shared during FGD was to be regarded as confidential.

Respondents were given enough time to explain their views. Each focus group was made up of 6-8 participants. Additional, probes were added to explore issues where the participants were unable to discuss all possible issues spontaneously

Each FGD took approximately 1hour. All the discussions were recorded and later transcribed. Participants were given some refreshments after each FDG.

In-depth interviews:

A total of 10 in-depth interview were conducted with managers, doctors, social worker and nurses working with children at UTH.

5.11. Data analysis:

Quantitative data was exported to SPSS version 17 for analysis. Simple frequencies were used to explore the data. The basic unit of analysis was individual patients. Chi-square was used to compare between categorical variables and t-test to compare continuous variables. Separate analysis were conducted for the PaedsQL4 and NEQ questionnaires.

Needs gap analysis: We calculated the needs gap by subtracting the % of those which said ―Yes” to requiring a particular need out of 23 items from those who said ―No”.i.e *Needs gap=(Yes%-No%) (Refer to Annex 7)*

Analysis of the PaedsQL4 tool:

We used the PaedsQL4 tool to collect information from guardians with sick children. The categories assessed include, physical, emotional, social and school functioning

We compared means across the three groups of patients using ANOVA with $p<0.05$ indicating a significant difference.

Factor analysis:

We performed confirmatory factor analysis to determine the factors loading of the items in the NEQ and PaedsQL4 tool. The rotational method applied was Varimax with Kaiser Normalization. Items were retained if they had a co-efficient > 0.5

Analysis of qualitative data

All qualitative data was transcribed, cleaned and validated by the Principle Investigator. The data was then exported to NVIVO software version 10 for analysis. The data analysis followed the conventional coding process beginning with a coding frame which formed the basis of initial data grouping. These were later combined and subsequently collated into relevant, larger thematic categories.

Data triangulation:

We explored same themes for example needs as assessed through the quantitative tools and needs as expressed through FGDs and IDIs. Though presented separately (quantitative and qualitative) in the discussion section of the thesis, these were combined and compared and contrasted.

5.12. Ethical consideration

In order to safeguard the interests of participants and to ensure that the study complied with research on vulnerable group the study obtained permission from University of Zambia Biomedical Ethics Committee and University of Cape Town. All participants were asked to provide written consent if they were able to write. Those who could not write were asked to thumb print the consent form in the presence of an independent witness. This research involved children so we acted to protect their interest during data collection [47, 48].

6.0. Results: Quantitative findings

6.1. Demographic characteristics of participants

Table 1: Sex distribution of children whose parents participated in study stratified by ward

		Sex of Child		Total
		Male n (%)	Female n (%)	n (%)
WARD	Oncology	15(75.0)	5(25.0)	20(100.0)
	HIV	37(52.1)	34(47.9)	71(100.0)
	General	7(38.9)	11(61.1)	18(100.0)
Total		59(54.1)	50(45.9)	109(100.0)

There were 109 children/guardian participants giving a tool number of 218 individuals. Most participants were from the HIV ward (71) followed by Oncology (20) and General Ward (18).There were 54% male participating children and 46% were female. *(Table 1)* The most common diagnosis in the general ward was malaria (40%).This was followed by pneumonia (26%).

Table 2: Age distribution of children whose parents/legal guardians participated in the study

		Sex of Child		Total
		Male n (%)	Female n (%)	
Age group (years)				
	< 1 year	6(46.2)	7(53.8)	13(100.0)
	1-5 years	21(48.8)	22(51.2)	43(100.0)
	6-10 years	22(62.9)	13(37.1)	35(100.0)
	11-16 years	10(55.6)	8(44.4)	18(100.0)
Total		59(54.1)	50(45.9)	109(100.0)

The age ranged from 0-16 years standard deviation 4.175. Mean age was 5.74. In terms of age distribution most participating children were aged 1-5 (43/109: 48.8% male and 52.2% Female). *(Table 2)*

Table 3: Sex distribution of Guardian/Parent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	18	16.5	16.5	16.5
	Female	91	83.5	83.5	100.0
	Total	109	100.0	100.0	

Most guardians were female 91/109 (83.5%) and majority of guardians were mothers (69.7%).Fathers were less than 15%. *(Table 3 & 4)*

Table 4:Relation of guardians to Child to children

		Frequency	Percent
Valid	Mother	76	69.7
	Father	15	13.8
	Other	18	16.5
	Total	109	100.0

Reliability and applicability of the needs assessment (NEQ) tool

Results showed that the NEQ tool was reliable for assessing palliative care needs in Zambian children a Cronbach's alpha 0.874 (i.e. >0.7) for the 23 items.

Factor analysis for the NEQ tool

The highest factor loading were in Information domain. Information about: Examination (0.852), treatment (0.832) and prognosis (0.769). Other factors which loaded highly were need for spiritual help (0.909), need for social insurance support (0.842) and psychosocial support (0.854) *(See table 5)*

Table 5: Confirmatory factor analysis for the 23 items for needs assessment

		Component					
	Physical	**Information**	**communication**	**Economic**	**Psychosocial**	**Spiritual**	**Relational**
I need more information about the child's diagnosis		**.697**					
I need more information about my child's future condition		**.769**					
I need more information about the examination done to my child		**.852**					
I need more explanations about the child's treatments		**.832**					
Need to be more involved in therapeutic choices of my child		**.510**					
Need clinicians and nurses to give me more comprehensible information			**.735**				
Need clinicians to be more sincere about the child's illness			**.729**				
I need to have better dialogue with clinicians			**.601**				
Need the child's symptoms (e.g.pain) to be better controlled	**.553**						
Child needs more help eating, dressing, and going to bathroom	**.625**						
I need better respect for our privacy							**.616**
I need better attention from nurses							**.525**
I need to be more reassured by the clinicians							**.657**
I need better services from the hospital (bathrooms, meals etc)							
Need to have more economic-insurance information in relation to my illness				**.842**		.	
I need economic help in caring for my child							
The child needs to see a psychologist our counsellor					**.854**		
The child needs to see a spiritual counsellor or priest						**.909**	
Child needs to speak with people who have this same experience							
I need to be more reassured by my relatives							**.670**
I need to feel more useful within my family							**.725**
I need to feel less abandoned							**.759**
I need to receive less commiseration from other people							**.849**

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Need gap analysis based on the NEQ tool

Generally there were very high need gaps across all hospital wards with 15/23 items having need gap of >50%.Overall the largest need was in the information domain. The item related to information about future prognosis (need gap 70.3).The second highest overall need gap were in item related to need for economic support. When wards were compared oncology ward 20/23 items had a need gap of >50%. Higher need gaps were noted in information about prognosis and economic support (need gap 90%).In the general ward, 19/23 item had need gap > 50%. The highest need gap of 100% was noted in information about the treatment given to children.

The HIV ward had least need gap with only 8/23 items having a need gap of > 50%.

In this group information about future prognosis again had highest need gap (63.4%)

Table 6: Needs Gap analysis for the 23 needs items

		Needs Gap (%YES-% NO)			
		Total	Oncology	HIV	General
1	“I need more information about the child’s diagnosis”	63.4	65.3	60.6	67
2	“I need more information about my child’s future condition”	70.3*	90*	63.4*	72.6*
3	“I need more information about the examination done to my child”	54.2	50	52.2	66.6
4	“I need more explanations about the child’s treatments”	59.6	50	52.2	100*
5	“I need to be more involved in the therapeutic choices of my child”	50.4	80*	40.8	55.6
6	“I need clinicians and nurses to give me more comprehensible information	56	70	43.6	88.8*
7	“I need clinicians to be more sincere with me about the child’s illness”	47.6	60	40.8	66.6
8	“I need to have a better dialogue with clinicians”	59.1	70*	52.2	77.8*
9	“I need the child’s symptoms (pain, nausea, insomnia, etc.) to be better controlled	52.4	50	46.4	77.8*
10	“The child needs more help with eating, dressing, and going to the bathroom”	-7.4	50	-29.6	22.2
11	“I need better respect for our privacy”	52.2	-20	15.4	33.4
12	“I need better attention from nurses”	52.2	70	46.4	55.6
13	“I need to be more reassured by the clinicians”	37.6	50	29.6	55.4
14	“I need better services from the hospital (bathrooms, meals, cleaning)”	26.6	80	1.4	71.6
15	“I need to have more economic-insurance information (tickets, in relation to my illness	54.2	50	60.6	88.8*
16	“I need economic help in caring for my child”	63.5	90*	55	66.6*
17	“The child needs to see a psychologist our counsellor ”	48.6	80*	38	55.6
18	“The child needs to see a spiritual counsellor or priest”	52.2	0	35.2	88.8*
19	“Child needs to speak with people who have this same experience”	46.8	85*	32.4	55.6
20	“I need to be more reassured by my relatives”	35.8	60	26.8	44.4
21	“I need to feel more useful within my family”	50.4	70*	40.8	66.6*
22	“I need to feel less abandoned”	26.6	40	19.4	43.4
23	“I need to receive less commiseration from other people”	-12	0	-24	22.2

Notes: Needs Gap =Y-N: It was calculated as proportion of who say Yes(Y) minus proportion of those who said no(N) to each item

6.2. Reliability and applicability of PaedsQL4 needs assessment tool:

Table 7 provides descriptive statistics of the items that make up the paedsQL4 needs assessment tool. Out of the 109 children, 64 attended school while the rest did not attend. Among all the children represented, the highest mean score was noted in pain and aches (mean 1.28, Std deviation1.248, feeling angry (mean 1.12 Std deviation 1.192). For the 64 patients who attended school, the highest mean scores was in missing schools to attend clinics (mean 1.91,std deviation 1.080) and missing school because of feeling unwell (mean1.62 Std deviation 1.162)

Table 7: PaedsQ4 assessments: Descriptive statistics for children admitted to UTH children, in Lusaka

Item	N	Minimum	Maximum	Mean	Std. Deviation
Walking few metres(5-10m)	109	0	4	.80	1.332
Running	109	0	4	.91	1.405
Participating in sports activity or exercises	109	0	4	.90	1.453
Lifting something heavy	109	0	4	.90	1.440
Doing chores(e.g. Picking up toys/helping at home)	109	0	4	.85	1.339
Having hurts/aches or pain	109	0	4	1.28	1.248
Feeling afraid or scared	109	0	4	.96	1.217
Feeling sad	109	0	4	.99	1.243
Feeling angry	109	0	4	1.12	1.192
Trouble sleeping	109	0	4	.54	1.076
Worrying about what will happen to him or her	109	0	4	.73	1.160
Getting along with other children	109	0	4	.74	1.279
Other children wanting to be his or her friend	109	0	4	.83	1.325
Getting teased by other children	109	0	4	.65	1.075
Not able to do things that other children same age do	109	0	4	.98	1.408
Keeping up when playing with other children	109	0	4	.90	1.312
Paying attention in class	64	0	4	.92	1.337
Forgetting things	64	0	4	.88	1.134
Keeping up with school work	64	0	4	1.09	1.377
Missing school because of not feeling well	64	0	4	1.62	1.162
Missing school to go to the doctor or hospital	64	0	4	1.91	1.080

Cronbach‘s test was used to assess the reliability of the 21 items that make up the peadsQL4.The results were separated for those items applicable to all (16 items) and those only applied to children attending school (5 items). Cronbach‘s alpha for the 16 items applicable to all children was 0.903 which is considered very reliable. Reliability for the 5 items which assessed school functioning gave a Cronbach‘s alpha of 0.744. *(See Table 8)*

Reliability test was done for the three wards to see if there was a difference in the reliability of the paedsQL4 in assessing patients with different problems.ie. Oncology or cancer, HIV and general paediatric problems. The results showed that Cronbach‘s alpha were all above 0.7 for all the three categories of patients. Cronbach‘s alpha was 0.882 for oncology patients, 0.893 for HIV patients and 0.897 for patients with general paediatric problems. (See Table 8)

Table 8: Reliability test for the paedsQ4 assessment tool

Group	*n*	*Number of items*	*Cronbach's Alpha*
All participants	109	16	0.903
Children attending school	64	5	0.744
Oncology	20	16	0.882
HIV ward	71	16	0.893
General	18	16	0.897

Note: Cronbach’s alpha >0.7 is considered reliable

There were significant mean differences across the three categories of patients in all domains of functioning with oncology patients performing worst. In physical functioning domain, the items showed that 6/7 items had significant mean differences ($p<0.05$). The only non-significant difference was noted in the item related to doing chores at home.

For the emotional functioning domain, 2/5 items showed significance difference between the three group of patients with $p<0.05$. These were having trouble sleeping and worrying about the future.

In social functioning, 3/5 items had $p<0.05$. These were: difficulty making friends, not able to do things that other children are doing, not keeping up when playing with other children.

School functioning domain showed significant differences across the three categories of patients in 2/5 items with $p<0.05$. The items were; forgetting things and missing school because of feeling unwell.

Table 9: ANOVA Comparing the mean between the three groups of parents in general, Oncology and HIV units

			Sum of Squares	df	Mean Square	F	Sig.
Physical functioning							
Walking few metres(5-10m) * WARD	Between Groups	(Combined)	17.064	2	8.532	5.183	.007
	Within Groups		174.496	106	1.646		
Running * WARD	Between Groups	(Combined)	35.276	2	17.638	10.515	.000
	Within Groups		177.806	106	1.677		
Participating in sports activity or exercises * WARD	Between Groups	(Combined)	25.988	2	12.994	6.822	.002
	Within Groups		201.902	106	1.905		
Lifting something heavy * WARD	Between Groups	(Combined)	31.979	2	15.990	8.832	.000
	Within Groups		191.911	106	1.810		
Doing chores(e.g. Picking up toys/helping at home) * WARD	Between Groups	(Combined)	2.991	2	1.496	.832	.438
	Within Groups		190.660	106	1.799		
Having hurts/aches or pain * WARD	Between Groups	(Combined)	12.308	2	6.154	4.185	.018
	Within Groups		155.876	106	1.471		
Emotional Functioning							
Feeling afraid or scared * WARD	Between Groups	(Combined)	7.164	2	3.582	2.487	.088
	Within Groups		152.689	106	1.440		
Feeling sad * WARD	Between Groups	(Combined)	6.727	2	3.363	2.225	.113
	Within Groups		160.264	106	1.512		
Feeling angry * WARD	Between Groups	(Combined)	2.206	2	1.103	.773	.464
	Within Groups		151.244	106	1.427		
Trouble sleeping * WARD	Between Groups	(Combined)	18.220	2	9.110	9.038	.000
	Within Groups		106.844	106	1.008		
Worrying about what will happen to him or her * WARD	Between Groups	(Combined)	16.228	2	8.114	6.664	.002
	Within Groups		129.056	106	1.218		
Social Functioning							
Getting along with other children * WARD	Between Groups	(Combined)	8.030	2	4.015	2.522	.085
	Within Groups		168.777	106	1.592		
Other children wanting to be his or her friend * WARD	Between Groups	(Combined)	11.780	2	5.890	3.509	.033
	Within Groups		177.908	106	1.678		
Getting teased by other children * WARD	Between Groups	(Combined)	1.760	2	.880	.758	.471
	Within Groups		122.993	106	1.160		
Not able to do things that other children his/ her age can do * WARD	Between Groups	(Combined)	20.848	2	10.424	5.722	.004
	Within Groups		193.115	106	1.822		
Keeping up when playing with other children * WARD	Between Groups	(Combined)	14.341	2	7.170	4.431	.014
	Within Groups		171.549	106	1.618		
School Functioning							
Paying attention in class * WARD	Between Groups	(Combined)	6.423	2	3.211	1.845	.167
	Within Groups		106.187	61	1.741		
Forgetting things * WARD	Between Groups	(Combined)	9.043	2	4.522	3.833	.027
	Within Groups		71.957	61	1.180		
Keeping up with school work * WARD	Between Groups	(Combined)	5.910	2	2.955	1.588	.213
	Within Groups		113.527	61	1.861		
Missing school because of not feeling well * WARD	Between Groups	(Combined)	9.468	2	4.734	3.823	.027
	Within Groups		75.532	61	1.238		
Missing school to go to the doctor or hospital * WARD	Between Groups	(Combined)	5.066	2	2.533	2.260	.113
	Within Groups		68.372	61	1.121		

6.4. Factor analysis of the paedsQ4

Table 10: Confirmatory Factor analysis for the 21 items making up the paedsQ4 tool

	Physical	*Emotional*	*Social*	*School*
Walking few metres(5-10m)	**.765**			
Running	**.896**			
Participating in sports activity or exercises	**.896**			
Lifting something heavy	**.715**			
Doing chores(e.g. Picking up toys/helping at home)	.484			
Feeling afraid or scared		.592		
Feeling sad		**.842**		
Feeling angry		**.666**		
Trouble sleeping		.298		
Worrying about what will happen to him or her		.106		
Getting along with other children			**.826**	
Other children wanting to be his or her friend			**.847**	
Getting teased by other children			.484	
Not able to do things that other children			.571	
Keeping up when playing with other children			.573	
Paying attention in class				**.716**
Forgetting things				**.625**
Keeping up with school work				**.643**
Missing school because of not feeling well				**.707**
Missing school to go to the doctor or hospital				**.842**

Confirmatory factors analysis showed that 2 items were loading highly on the physical functioning factor. These were running and participating in sports (0.896).In the emotional functioning domain, 2 items loaded highly on factor analysis, feeling sad (0.842 and angry (0.666).In the social functioning domain, highest loading were in 2 items, both related to making friends i.e. getting along with friends (0.826) and friend wanting to be friend (0.847).

In the school domain missing school to go to hospital loaded highly on factor analysis (0.842) followed by difficulty paying attention in class (0.716)

7.0. Results: Qualitative findings

Qualitative results were categorised into themes and subthemes. These are summarised table 11 and expanded in the following section.

Themes and subthemes identified	
Main themes	**Subthemes**
Knowledge about Palliative care	Components of palliative as reported by respondents
	Palliative care for children
Understanding of children's problems	Parental understanding of Reasons for admission
	Common problems affecting children
Capacity to deliver palliative care services:	Training in palliative care by health workers
	Presence of Multidisciplinary team
	Assessment of palliative care needs for patients and families
	Referral system for patients and family
Important needs Palliative care needs for the families	Bereavement support Physical symptom management
	Economic support for families
	Recreation facilities at the hospital premises
	Psychological support
	Spiritual support
Communication	Communication of diagnosis and management to families
Experience with palliative care services	Help given to families and children since admission
	Satisfaction with a palliative care services received

7.1. Knowledge about Palliative care

7.1.1. Components of palliative as reported by respondents

Parents and guardians were asked about what they understood by palliative care. Most of them did not know about palliative care as a term but understood it when it was explained to them. They were asked about what is involved in palliative care. Majority of the participants talked mainly about physical support. Psychological and spiritual care were only mentioned after further probing as most respondents did not think it should be provided by the hospital. They reported that they had seen the catholic chaplaincy service at the hospital. Those not belonging to this denomination did not think they were supported by this service. It was also reported that some church organisations occasionally came around and talked to patients and families. In terms of importance, all respondents agreed that it was an important aspect of care that families needed but it was not well coordinated. Most health workers were aware about the definition of palliative care and its components. They also acknowledged that it was not available as part of the comprehensive care at the hospital.

" Palliative care is the type of care that looks at people who are chronically ill, for example cancer, HIV and many others, so there is need for care on the physical pain their body experiences for example when they have body pains, you give them a pain killer and life is enhanced, a counsellor comes and talks to you and help calm your heart, maybe church brethren come such as the pastor and they pray for you, all this is put together is what you call palliative care."
Sister in-charge

"Helping those who are chronically ill so that there days and supplemented"
Male FDG respondent

"it is a way of managing children who have possibly life threatening conditions, because the children can still live their life span, to manage them, for their conditions that they have, but when I say conditions I just don't mean the physical conditions because in palliative care the way we manage them and the way I think it is, you manage them not just the physical condition but also manage their social condition, emotional condition, spiritual condition and any other condition including economic condition, it is very wide and it starts as soon as you have contact with the patient, you don't wait until the patient is dying and that is when you say we have palliative care no, it starts immediately the patient comes".
Paediatric consultant

7.1.2. Palliative care for children

WHO differentiates palliative care for adults and children. Most of our respondents were able to distinguish that palliative care in children is different from adults. They acknowledged that provision of palliative care in children is more challenging because of the family dynamics and that children were unable to articulate their needs compared to adults. It was generally observed that most of palliative care provided for children was directed towards physical support and it was not family centered. Others services like spiritual and psychological care were not routinely provided.

"Palliative care is a way of managing children who have possibly life threatening conditions, because children can still live longer after diagnosis.... it is difficult and complex to manage children ..... you manage them not just the physical condition but also manage their social condition, emotional condition, spiritual condition and any other condition including economic support'

Sister In-charge

Respondents were asked about the presence of a dedicated unit or ward that provided palliative care at the hospital. It was noted that this was not available at UTH and there was no formal arrangements with hospices to take children requiring palliative care. The unit providing some kind of palliative care was the oncology ward and most of the services were limited to physical care to some extent pain relief.

"Concerning a ward dedicated for palliative care, we don't have a structured palliative ward"

Clinical Manager

7.2.Understanding of children's problems

7.2.1. Reasons for admission:

We asked parents and guardians if they knew the reason why their child was admitted to the hospital. Most of the reasons given by parents were none specific. Most did not know what was wrong with their child and talked about symptoms. Parents with children with haematological problems and HIV were much more aware about the reasons for admission or visiting the hospital. This was less so for oncology patients and general wards. One respondent said:

"...he started feeling pain in the hands and the legs and also started feeling week, we then brought him here at the hospital and they gave us an appointment, the appointment was quiet long and in the process of waiting the child's legs started swelling".

Male FGD respondent

7.2.2.Common problems affecting children

Parents were asked about the common problems affecting their sick children. Most common problems in order of significance were loss of appetite, pain, loss of weight and a drop in the body cells among others especially for oncology patients on chemotherapy. For parents with HIV positive children the major problem was that their children often missed school to come for treatment and investigations. These were not done over the weekend for stable patients.

" I brought my child here because of low blood levels in the body and he also had malaria…he was really sick and that is how I took him to the clinic and that is where they diagnosed him as having less blood in the body and that is how they referred me here, but from the time we have been here, they have done blood transfusion and medication for malaria was given,. He is now complaining about a headache and stomach ache"

Female FDG respondent

"Ok yes but the problems the children are experiencing are bad, some are vomiting, losing appetite, abdominal, headaches, then… diarrhoea so many of them.

Female FDG respondent

7.3. Capacity to deliver palliative care services:

7.3.1.Training in palliative care by health workers

We asked both managers and health workers about availability of trained health workers in palliative care. Managers acknowledged that there were very few nurses and doctors trained in palliative care. Those who were trained were mainly through short courses arranged by the Palliative Care Alliance and other partners. There was no formal training in palliative care and there was no one with formal qualification in palliative care. This finding was evident when doctors and nurses who were working on the wards were asked about training in palliative care, they denied having formal training. Interestingly, the rotation system for doctors and nurses did not consider training or experience. Those trained could be transferred to other units and those untrained were brought in. This showed that available and experienced health workers in palliative care were often misplaced. This was attributed to the fact that UTH is a teaching hospital and rotations and moving out was the way the system works.

"I think there have been attempts to provide palliative care training for health workers,… but this should be done maybe at a unit level,….sometimes you have high turnover of the staff so that you may find that some who have been trained leave and replaced by new ones who are not trained in palliative care"

Clinical Manager

"This is a teaching unit, right now I'm the only permanent staff that is here, all these you saw here are in and out, they are here for four months and they go. Some of them are here for one month and they go"

Sister in-charge

7.3.2. Presence of Multidisciplinary team

There was no formally recognised multidisciplinary team. Nonetheless, there were individuals who were employed by the government to provide support to patients and families. There was a social worker who worked alone and lacked recognition and worked in isolation. Doctors requested a social worker to come and see the patients and families but there was no way of feeding back or sitting together to plan for patients. This was true for chaplaincy and occupation therapy. These too were consulted but were not included in the discussion of patients and family care .The referrals to these groups were also random and not formalised making most patients unable to benefit. The public relation office was also noted to provide some support but this too was not well known by most respondents. In summary, there was no team to coordinate palliative care services

> *"We do not have a team or unit that coordinates palliative care..... however, we do have an office of the customer relations or public relations officer... though majority of our patients may not be aware and it is something that we need to make more visible"*
>
> ***Clinical Manager***

> *"Yes, there is no specific palliative care unit we only have individual doctors and the nurses. Sometimes we also have a spiritual specialist coming in.....but we should be able to have a team that is readily called upon. We should be able to say here are spiritual issues come in and counsel this one and other needs, but it is not coordinated, we have some sort of team but it is not cohesive.*
>
> ***Paediatric Consultant***

7.3.3. Assessing of palliative care needs for patients and families

We asked both mangers and parents if the hospital formally asked about palliative care requirements and needs. The managers agreed that there was no policy, system or guidelines for assessing palliative care needs for patients and their families. There were no tools or guidelines to assess these needs. Individual doctors and nurses used their experience to assess the needs. This was true for pain assessment, there was no standardised tool for pain assessment and health workers waited for patients to complain of pain before they gave pain relief. This resulted in many families missing out on the help which could be available but no one knew whether the patients and family needed that help. The social worker seemed to assess social needs but this too was not standardised.

"We don't have standardised tools to formally assess children for palliative care needs. We just go through the general clinical evaluation and then at the end individual doctors decide what is required based on their experience"

Clinical Manager

7.3.4. Referral system for patients and family

We asked both managers and families if there were any formal referral channels to other units or specialists within or outside the hospital

The results showed a mixed picture about the referral system. Most mangers said there was a referral system through sending consultations to other specialists including occupation therapist, social workers. Nonetheless, due to lack of coordination, most referrals were not followed through and there was no feedback as to whether the patients and families had received the requested help or not. Individual doctors used their discretion to refer patients and it was not clear how many people benefited or lost out on available services due to poor referral coordination

"There is no formal system of referral, but when we identify that there is a need that a social worker can help with.... we simply call or send a referral consultation form to the social worker.... the spiritual counsellors are unreliable...they only come when they decide to come ...we have tried to get people in place but it has not worked very well"

Sister In-charge

7.4. Important Palliative care needs for families

7.4.1.Bereavement support

We asked families about the most important need that was not met by the hospital. Bereavement support was among the most important unmet needs. Most bereaved families lacked support and were left on their own. Most had travelled from far away and did not have money to return and the hospital did not provide any bereavement support. Well-wishers from nearby churches sometimes helped families if they were asked or when they accidently passed-by the ward on their routine hospital outreach. Sometimes the social workers helped with transport costs but due to poor funding they could not guarantee such support to the bereaved families.

"No there is no any form of bereavement support...maybe I should put it this way...which actually hurts me...For instance when a child dies ...what you see in this hospital are relatives wailing and crying but there is nobody from the hospital to comfort them"

Paediatric consultant

> *"If you lose a child in this hospital you are on your own….There is no support given to families who have lost children on this ward. Most of them don't have even transport to go back and later on take the body back for burial"*
>
> ***Female FDG participant***

7.4.2. Physical symptom management

Majority of participants in FDGs complained that their children were in pain and pain killers were only given if requested. They usually were given paracetamol even when the child was in severe pain. Parents wanted their children to receive regular and stronger pain killers. This was noted especially in the haematology ward were children had sickle cell disease and the oncology unit.

> *"Our children are in severe pain but they are always given Panadol….even when you complain nothing is done"*
>
> ***Female FDG participant***

7.4.3.Economic support for families

Most families were from distant places and were referred to the UTH where they had no family support or any source of income. This disrupted family life. They faced many financial challenges ranging from transport and accommodation to food.

This was made even worse for cancer patients who had long treatment regimen requiring them to stay for several months without support. This results in some parents taking away their children before completion of treatment. The food provided by the hospital was mainly for children and parents were generally not given food. There was also limited accommodation especially for men who spent nights on the bed side for prolonged periods of time. There were also no good sanitary facilities for families and no place to do their cooking.

One complaint by parents with oncology patients was that when they were being referred from the local hospitals they were not informed about the possibility of long stays and were unprepared and were often surprised how long it takes to finalise investigations and complete treatment.

> *"Just as I said that…the child has died that side because of vomiting, there is no drug. Now if you stay in the hospital for many days or many months, they tell you to go and buy the drug, how can you buy the drug you don't have money? They examine the child and then tell you to go to the social worker….you get to the social work that I want money for drugs and they tell you they have not received any money from government…"*
>
> ***Male FDG, participant***

7.4.4 Spiritual support

Families reported that spiritual support was very important but it was not routinely available. The chaplaincy office was more concerned with Catholics and others felt uncomfortable to seek help from a catholic priest when they were Protestants or Muslims.

> *"The church people help, but it is not that they come all the time, but they seem to come when you are feeling bad in your heart, and you have lost hope and they encourage you. Like for me, I used to lose hope because my child used to improve and again go down and this made me lose hope, but when people from church came, it made me feel that God is"*
>
> ***Male FDG participant***

> *"The church also do come, different types they come sometimes, they give us just like that. They encourage us just you heard that we suffer when we do not have, when body cells in a child drop, at that time the child needs fruits. The fruits are expensive we do not manage. Sometimes when you are in need, you see people from the church have come. They come with oranges you are luck, apples and some bananas, just like that that is how we survive. Yes that is how we survive otherwise without that, we would have failed since we don't have where to touch"*
>
> ***Female FDG respondent.***

7.4.5. Psychological support

Most respondents felt that their problems needed to be discussed with someone who had experience in supporting families in difficult situations to help them cope with their challenging situations. The help of psychologist or counsellor would help the families and their sick children.

> *"Cancer is very big problem for the child and family. We need to receive counselling support so we can learn to live with our challenging circumstances…even children need counselling"*
>
> ***Female FDG participant***

7.4.6 Recreation facilities at the hospital premises for families

There were very limited recreation facilities for children admitted to the hospital. Most of the parents would have loved to see their children get out of bed and do some recreation activities.

"Children have nothing to in in this place for entertainment….even when they feel better they can't play any games outside….they are bored"

Male FDG participant,

7.5. Communication

7.5.1.Communication of diagnosis and management to families

Communication is a key element of providing quality care. We asked parents and guardians about their experience in communicating with health workers. Most respondents in the oncology and general ward were not informed about what was wrong with their children and what the prognosis was. They usually learnt when they over heard the doctors discussing in English about the patient. Most parents expressed frustration with discussing their child's illness with health workers. They were left in the dark and didn't know what to expect. This if reflected in the following quotations:

—.as for me, they mentioned or talked about it, but they are not sure, they are still going to tell us, so we are still waiting for one more test from another hospital and that is when we will know how the problem came about and the solution to the problem"

Female FDG participant,

"I have not yet received assistance because they steal don't know the problem that is causing the child to have pain in the stomach, the child does not even go to the toilet..,".

Female FDG respondent,

"..they [doctor]speak in English among themselves. You find that they come as a group and begin to speak among themselves in English……They don't even explain anything to us, you find that they just start the treatment without explaining anything to you".

Male FDG participant

The situation was better for parents with HIV positive children who were well informed about the illness. The major challenge in this group was that some of the parents had not discussed the diagnosis and prognosis with the own affected children even when they were encouraged to so. Nonetheless, majority of the parents had disclosed this to their children

7.5.2. Feelings experienced by parents when they learnt about the child's illness.

We asked parents and guardian how they felt when they first learnt about the diagnosis of their children. The reaction of most parents after learning about the child's illness were generally similar and could be summarised as:

confusion, isolation, abandonment, shock, unexpected and stressful. This was complicated by the need to travel to strange tertiary centres for treatment where there was little family and community support.

All respondents did not feel well when they learnt about the illness of their children. The information about the child's illness brought a lot of panic and suffering as parents did not know what to expect and nobody was explaining to them the expected outcomes. Following are some experiences from some of the respondents:

> *―My child's disease has made me move up and down a lot, since she was 7 years, it has been like that, others even say is it witchcraft, I even went to traditional doctors and was cheated and I came back, I then stopped and started going for prayers, then I just decided to place everything in the hands of God and stated bringing this child to the hospital.*
>
> ***Female, FGD respondent,***
>
> "
>
> *―when my child was sick, they gave me a referral letter, I did not even know what to do with that referral paper because I didn't even have transport money to come here, ...no one even told me if there is any transport or ambulance to bring me to the hospital ....I really suffered I just kept on crying for two days"*
>
> ***Female FDG respondent,***

7.6. Experience with palliative care services

7.6.1. Help given to families and children since admission

We asked parents and guardians what help their children received since they came to hospital. Majority had received treatment targeting the main problem for example cancer but no other symptoms which they felt were also very important. Some of the respondents said that they were still waiting for the diagnosis and had not received any help.

For those whose children were on chemotherapy, the biggest nightmare was when the body cells dropped following chemotherapy. Most associated this with poor prognosis and worried that their child would die. This is a well-known and expected side effect of chemotherapy but this was not well communicated to the parents.

> *"Ok since we came doctors are working well, our children are improving. When they are given chemotherapy the disease improves, if it does not improves they change the drug, they give a different protocol. They try it and if it's not that they will refer us to CBH so that they test to know the disease is improving. If it's not that they will do a lumber puncture and bone marrow to see how the cancer is progressing in the body"*
>
> ***Male FDG respondent***

7.6.2. Satisfaction with a palliative care services received

Most respondents were happy with medical management of the patients but were not happy with the support given to families looking after the children. The services were said to be less family centered. This was even more difficult for men who had no shelter yet they were expected to be present for extended period of time. They also were not satisfied with the information which was given to them concerning the illness of the child.

They also complained that they had to pay for certain medical tests and sometimes the results took too long to come out, making families to travel several times between home and hospital which was costly to the families. They also did not like the tendency to be seen by medical students who were just asking questions and not providing any tangible help.

> *"..I think the doctors are good at giving chemotherapy.....but we have many issues for example, there are is no accommodation and no food for parents. It is very difficult for most of the parents as most of them have travelled from very far and they don't have family support..."*
>
> ***Male FGD participant,***

Summary findings

The findings indicate huge needs gap for child palliative care services in Zambia. The major family needs were economic and bereavement support. There was high demand for information for families which health workers did not adequately provide.

Pain control remained sub-optimal especially for children with cancer. One major barrier identified to provision of palliative care was poor coordination of services. This study is the first to validate and apply the NEQ and PAEDSQL4 tools for assessing palliative care in children in Sub-Saharan Africa. The major strength of our approach was that we used both qualitative and quantitative methods to triangulate data sources. This allowed for validation of some quantitative findings and in-depth exploration of some issues which could not be addressed quantitatively. Another strength was that the study collected information from both provider and user perspective, hence providing a fairer representation of issues affecting supply and demand of palliative care services in the Zambian context.

8. Discussion

The study had four major objectives:

1. To describe the socio-demographic characteristics of children with chronic illnesses at university teaching hospital
2. To evaluate tools for assessing palliative care in children.
3. To determine palliative care needs in children with HIV at University teaching hospital as described by parents/legal guardians and hospital staff
4. To establish palliative care needs of children with Cancers at University Teaching hospital (UTH) as described by parents/legal guardians and hospital staff

In answer to objective 1 and 2, the study found that children needing palliative services were found across all the hospital wards at the UTH. These patients were found in the cancer ward, HIV and the general wards. In each of these wards, there were unmet palliative care needs for children and their families. In our sample we found more HIV positive clients compared to cancer patients. The HIV ward is run as an outpatients department and has a huge volume of patients and supported by PEPFAR. The study also showed that children needing palliative care services are very young and might not be able to express their needs. Hence, the need to equip health workers with paediatrics palliative care skills. Demographics for parents and guardians, revealed that majority were female and were mothers to children. Men consisted a smaller percentage of care givers. This finding is unsurprising other studies have shown that the burden of care for sick children usually falls on women [49, 50].

In answer to specific objective number 2, the study evaluated the applicability of two new tools for assessing palliative care needs in children. These were the PaedsLQ4 and the NEQ. These tools have never been applied in low income settings. Our results showed that these tools were fairly reliable in assessing palliative care needs in children. Both tools gave Cronbach‘s‘ alpha of greater than 0.8. We used the NEQ to calculate the palliative care needs gap in the children admitted to the University Teaching Hospital. We noted that there were huge unmet needs for children and their families. Generally, there were huge palliative care needs gaps with 15 of the specific needs assessed revealing a need gap of over 50%. This tool has previously been applied to adult patients but has never been applied in children or low income settings [42]. It will be interesting to see how this tool compares with the APCA POS for Children which is being piloted in some African setting[45]

Palliative care needs

In terms of symptoms management, pain remained the highest unmet need for children admitted to the University teaching hospital. These findings were supported by the qualitative study findings where most parents expressed concern that their children were receiving in adequate pain relief. This problem was more pronounced among children with cancer. In addition, children on the general ward also reported inadequate pain relief. Other studies have also reported that pain management is a big challenge in sub-Saharan Africa [51, 52]. This has been attributed to inadequate knowledge on pain management by clinicians and inhibitory laws that prevent access to morphine [51, 52]. This might be true for Zambia where palliative care training is not routinely taught to clinicians and the laws still prevent wide access to morphine as it is still considered a controlled drug.

Missing school was one issue that was raised by most families. For children admitted or needing to attend clinics, they missed a lot classes and this was affecting their performance. This need has not been adequately addressed as classes for those admitted are not routinely offered and those attending clinics were given dates which conflicted with their school calendar. It has been recognised that provision of palliative care for children includes access to education and address their development needs[1]. It is therefore crucial that children admitted at UTH have access to education support and those required to attend outpatient clinic are given appointments that do not conflict with their school schedules.

When we compared the three groups of patients i.e. oncology, HIV and general ward using the paedsLQ4, we found significant mean differences across the three categories of patients in all domains of functioning. Oncology patients performed the worst in all functionality domains. We performed a confirmatory factors analysis to identify items with higher loading from the paedsLQ4 tool. Two items loaded highly on the physical functioning factor. These were running and participating in sports.

These findings support the need for pain control and enabling environment for children to play even when they are unwell. Playing is an important part of child growth[22]. Our qualitative results also confirmed the lack of recreation activities for children admitted to the University teaching hospital in Lusaka.

In answer to specific objectives 3 & 4, the study highlighted several needs by parents/guardian and health workers. The major family's needs focused on economic/financial and bereavement support.

Economic/financial needs

It was clear that most families were referred to the UTH from very far off places without any form of support. Most families expressed need for financial support which could not be provided by the hospital. The fact that many were required to stay for longer period of time to complete investigations and treatment, meant loss of wages and family support. While on paper the social worker is supposed to meet the need for economic and financial support, in practice the office of the social worker was inadequately financed so could not meet the demands from parents and children.

The centralisation of the treatment center in Lusaka was a huge burden to families. They were referred without assurance for support in terms of accommodation, transport and money for up-keep. Food provided by the hospital was not only bad but also only meant for the sick children. Parents were not provided with food.

It is important to appreciate who gets sick the most and therefore pays highest levels of out-of-pocket expenditure on health. The current health financing system in Zambia is characterized by high out-of-pocket spending on health, which is incurred at the point of service delivery [54]. This is a fundamental barrier to accessing health service. Currently there are global discussions about Universal Health Coverage (UHC) where governments are being compelled to find financing mechanisms that protect poor families from catastrophic health expenditure [55]. In Zambia there are discussions about introducing social health insurance [55]. These initiatives might mitigate some of the economic issues raised by families in this study.

Bereavement

Lack of bereavement support was another major gap in palliative care services. Families who lost their child were left to mourn on their own and arrange transport to take the funeral to wherever they were referred from. There was no bereavement support team at the hospital to support bereaved families. This was of concern to most parents who worried that if their child died then they would have to go through this process without support.

A recent systematic review on hospital based bereavement support by Donovan LA et al, in 2014, showed that family members who felt better supported during the loss of their child reported a reduction in sense of isolation, and improved coping and personal growth. The study also reported the need to offer support as a continuum from the time of diagnosis through death and beyond (World Health Organisation, 2006) [56].

Our study demonstrated lost opportunities to provide bereavement support to vulnerable families. This is an area which the hospital administration could address by using the already existing structures and human resources. For example, the office of social worker can coordinate the bereavement service with support from trained counsellors and nurses in bereavement team.

The study also showed the desperation that parents of children with life-limiting conditions go through in Zambia. When a diagnosis of life limiting illness is made for one of the children in the family, there was huge anxiety and disruption to family life. The loss in the family also affected remaining siblings. Most families felt unsupported emotionally and recommended that having a counsellor or psychologist would help them to cope in such circumstances [56]. Unfortunately, this service was not routinely available at UTH.

Information needs

There was generally a very high need for information for families which health workers did not adequately provide according to the respondents. This was true for diagnosis, prognosis and expectations. The problem was worse in the oncology and general paediatric wards. Parents with HIV positive children seemed to receive better information with respect to management and prognosis. This could be attributed to the fact that, there were more trained health workers in HIV counselling and that the service is running as a separate service with good funding support from partners such as PEPAFR. This was in sharp contrast to other wards which were dependent on government support.

The services provided were inconsistent and lacked coordination. For example some form of spiritual support existed but were not known. Families expressed desire to receive spiritual and psychological support, but how and when to access this service remained unclear for most parents. The emphasis of care seemed to be on physical symptoms where clinicians and nurses provided medical treatment directed at a specific disease with less focus on symptom management which was of concern to parents. Most parents were worried about nausea, weight loss and pain but these were not given priority. Poor communication did not help in this matter as families were not able to share their needs with clinicians who seemed to be overwhelmed with work and only talking among themselves in English which most parents did not understand well.

Training in palliative care

The study revealed lack of training in palliative care for all levels of health workers. Those trained were mainly through short courses provided by partners such as the Palliative Care Alliance of Zambia. Rotation of health workers compounded this problem. We found that, there were huge disruption in palliative care service provision when experienced nurses and doctors were rotated to other sections of the hospital were in most instances there were no longer dealing with palliative care in their new roles. Those brought in were untrained in palliative care. This rotation policy was negatively affecting the quality of palliative care which was being provided at the University Teaching Hospital.

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How to address the palliative care needs gap

The World Health Organization (WHO) pioneered a Public Health Strategy for integrating palliative care into a country's health care system. This strategy included advice and guidelines on how governments can priorities and implement both national palliative care programs and national cancer control programs where palliative care is one of the four key pillars of comprehensive cancer control. The WHO PHS addresses 1) appropriate policies; 2) adequate drug availability; 3) education of policy makers, health care workers, and the public; and 4) implementation of palliative care services at all levels throughout the society. This approach has demonstrated that it provides an effective strategy for integrating/establishing palliative care into a country.

In our study we found that there was no clear policy or guidelines on palliative care provision. In addition, there were no tools or standards for identifying palliative care needs. Everything seemed to depend on individual clinicians who themselves had no palliative care training. Parents and guardians wanted doctors to control the pain which was one major problem affecting children. However, our findings indicate that clinicians were still unwilling to give stronger pain killers such as morphine. There was still fear among some doctors to use morphine even when it was indicated. Severe pain was still managed with simple analgesia. This was attributed to lack of training in palliative care.

We noted that while some elements of palliative care were available, these were poorly coordinated. This could be attributed to the absence of multidisciplinary team to coordinate the services. This team is urgently required to help improve coordination and hence quality of palliative care services at the UTH. Provision of palliative care require policies and guidelines that provide directions and standards for palliative care [1]. Our study found lack of policy and guidelines for providing palliative care. In addition, there were no tools for evaluating palliative care needs or managing palliative care symptoms such as pain scores. We recommend that management consider introducing a policy on palliative care service provision and come up with standards. The Palliative Care Alliance of Zambia has been working on some of these issues and the hospital should collaborate with such institutions to improve access to quality palliative care services for children in Zambia.

Our findings can be applicable to other Sub-Saharan countries though we recommend that the tools be contextualised before being used. The study was done at the main referral hospital and hence some of the needs could be different from those in districts and rural areas. It is therefore important that similar studies are done in other settings to determine if the needs are similar or different.

Study Limitations

The study had several limitations which must be considered when interpreting the study findings. Firstly this is was across section study and hence it is not possible to provide linkage between cause and effect. Secondly, the study was done at the main referral hospital. This is selected group of patients which might not be a

representative of palliative care needs in Zambia. It is therefore important to conduct similar studies in other settings such as districts hospitals and smaller health facilities to determine if the palliative care needs are similar to the UTH. Thirdly, this study is limited by the possibility of information bias as respondents were in the hospital settings. It was possible that parents could have exaggerated the needs in order to get some help while health workers could have been protective of the institution hence giving false information. We triangulated data sources to minimise this risk.
Finally, this study collected information from parents and guardians only. Sick children were not directly interviewed. The study was conducted before the APCA Children‘s POS was published. Therefore there is need to compare results from this study and the APCA Children POS to establish concordance.

9. Conclusion:

This study applied two quantitative tools for assessing palliative care needs in Children. The results showed that the tools were fairly reliable and applicable in the Zambian context. The findings indicate a significant needs gap for children‘s palliative care services in Zambia. The major family needs were economic and bereavement support. There was high demand for information for families which health workers did not adequately provide. Pain control remained sub-optimal especially for children with cancer. One major barrier identified to provision of palliative care was poor coordination of services.

10. Recommendations

Policy makers:

Ministry of health

- During the study it was noted that there were no national policy and guidelines to guide provision of Palliative care services at national and local level. The MoH should therefore support development of national policy and guidelines on palliative care service provision in the Country and ensure that these are implemented. There is no formal structured training in palliative care in the Country. Most people trained in palliative care were through short courses which were not well coordinated. It is recommended that MoH work with local Universities to provide structured training in palliative care for doctors and nurses
- There are concerns about morphine availability and restrictions in prescription. It is recommended that the Ministry works with relevant stakeholders to review the law concerning morphine control, so that access is not limited for those who would like to legally use morphine for pain relief
- There is limited literature on Zambia specific palliative care services and limitations. The Ministry support and encouragement of research in palliative care to guide policy and practice would be helpful
- The study found that most patients and families had travelled long distances to come to UTH to access services especially cancer treatment. It is recommended that the Ministry consider decentralised cancer treatment to avoid long distance travel for patients
- The social welfare office had limited resources to attend to huge need which families required. The ministry must lobby government to increase funding and resources to the health social welfare office at UTH.

University teaching hospital (UTH)

- The study revealed that there was no team to coordinate paediatric palliative services at UTH. It is recommended that a multidisciplinary team to coordinate palliative care services be establish.
- One challenge with continuity of providing palliative care was the rotation system which is practiced at UTH. While it is not possible to completely do away with staff rotation, the hospital must ensure that trained staff in palliative are not misplaced.
- Children need to play even when they are in hospital. The lack of amenities at UTH limited this children‘s right. It is recommended that UTH management with its partners provide amenities to enable admitted children to play free while waiting to be discharged.
- Families felt unsupported when they lost a child. There was no one to comfort or encourage them and help with the logistics. It is therefore recommended that a bereavement support team be formed to help families who are bereaved.
- Caregivers were not provided with food or accommodation yet spend night and days on the bedside. The UTH management should consider proving food and accommodation for caregivers as well.
- There were still misconceptions and fear to use morphine by many health workers. The hospital must encourage doctors and nurses to use morphine when it is indicated
- The tools used in this study showed that they are applicable in the Zambian context. UTH can use the tools developed to assess patients and family needs
- The hospital lacked palliative care guidelines and standards for children. The hospital should work with the Palliative Alliance of Zambia to develop paediatric specific guidelines and standards to guide provision of palliative care.
- The study showed that many children were missing school to attend hospital appointments and those admitted did not have access to teachers. The UTH must support school friendly patient appointments

and ensure that classes and teachers are available for children who have been admitted

- Families expressed desire to talk to a counsellor of psychologist about the problems and challenges but these were not readily available. Through a multidisciplinary team the hospital should provide access to counsellors or psychologist for families and children.

Researchers:

- The study has shown many gaps that need further research. For example the tools were only applied at an urban referral hospital which might be different from districts and rural settings. It is therefore recommended to validate the paedsQL4 and NEQ tools in other settings
- The recently published APCA Paediatric POS should also be assessed as a possible research and quality improvement tool in Zambia.
- The study only collected data from parents and guardians. Children were not included. It will therefore be interesting to apply the paedsQL4 and NEQ directly on children which was not done in this study.
- There is an opportunity to conduct an experimental study to longitudinally assess the change in the needs gap in response to specific interventions.

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12. APPENDICES

ANNEX 1A: Information for paediatrics palliative care needs study

Dear participant
You are invited to take part in a study to find out needs of children and their families who are affected by Cancer or HIV infection. We will be carrying out this study at the University teaching hospital which is our main referral hospital in Zambia. Information on the study is supplied in this document. We want you to know the purpose of the research, the possible risks and benefits and what will be expected of you if you decide to participate. If you agree to take part in this study after it has been fully explained to you, you will be asked to sign this consent form. You will be offered a copy to keep. This process is called informed consent.
Please note that:
Your participation is entirely voluntary.
You may decide not to answer any or all questions at any time.
You are free to ask questions before signing this form and if you have other questions during the survey, you may contact researchers conducting the project.
You will be provided with this information in writing and/or had it read to you by a research assistant from the project.
A copy of this document will be offered for you to keep

Who is doing the study?
This study is being performed by Dr.Wilbroad Mutale with support from the Palliative Care Association of Zambia and the Ministry of Health.
The full contact address for the principal Investigator Dr.Wilbroad Mutale is:
University of Zambia School of Medicine
P.O Box 50110, Lusaka:
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This research protocol has been approved by the University of Zambia Research Ethics Committee:
The Chairperson
Research Ethics Committee
University of Zambia
Ridgeway Campus
P.O Box 50110
Lusaka, Zambia
Tel/Fax 021-1250753
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And by the University of Cape Town Human Research Ethics Committee
c/o Mrs Lamees Emjedi
E 52, Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Cape Town
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What is the purpose of the study?

The study involves mainly asking questions about the experience of children and their families with chronic illness especially cancer and HIV infection. We would like to know what special needs children and families have in order to guide provision of better care for the affected children and their families. We will ask you some questions to get more details about yourself and your living conditions at home and here at the hospital. We will also ask you questions about how you or child is coping with the illness. We will ask you about any help that you think could help you better cope with your situation. In order to ask the questions we have developed a questionnaire to guide us in asking questions.

What is the benefit to you of taking part in this study?

There may be no direct benefit to you from this survey. However, information learned from this study could be used to improve services for children and families suffering from chronic illness in Zambia. We still do not know what special needs these children and their families require so when you take part you will be helping us to find out what these needs are and how best to provide help.

What are the Risks, Stresses and Discomfort of taking part in this study?

Risks of participating in this study and answering the questionnaire are minimal. However some of the questions may be sensitive or may cause you to worry. You may choose not to answer any of the questions if you wish.

Confidentiality of information and privacy of the participant

All personal information obtained during this study will be kept strictly confidential. The answers will be entered in a hand held computer, but your name will not be included, and you will be identified by a coded number only.

No information about you will be released to anyone but the research team, without your further consent. The data may be published but your name will not appear.

Withdrawal without Prejudice

Please be informed that you may withdraw your participation at any time without penalty. Your refusal will not affect access or quality of health services here at UTH or elsewhere for you or you sick child.

Alternatives to Participation

The alternative to participation is not to participate. There is no penalty if you choose not to take part in the questionnaire. Should you decide not to participate, this will not affect the services you are receiving now or in the future at this hospital

Costs to You

There will be no financial cost to you for participating in the questionnaire.

Compensation for Your Time and Travel

You will receive no compensation for participating in the questionnaire.

Legal Rights

You do not give up any legal rights by signing on this consent form.

Thank you for reading this information sheet. If you have any questions, please ask them now. I will be pleased to answer them. If you wish to take part, please read and sign the consent form. Please keep this information sheet in a safe place.

ANNEX 1B: Informed consent form for the paediatric palliative care needs study (adults)

1. I confirm that I have read the information sheet, and that the information about my taking part in this survey have been explained to me.
2. I confirm that I have had the opportunity to ask questions about the study and that I am satisfied with the answers provided.
3. I have been given time and opportunity to read the information carefully, to discuss it with others and to decide whether or not to take part in this study.
4. I understand that the researchers will keep all my personal information confidential.
5. I understand that I will not get any financial reward for taking part in this study.
6. I understand that the results of this study may be published in scientific journals but that my name will not be used.
7. I agree to take part in the survey.

Subject‘s signature/fingerprint: ________________________________ Date ________

Subject‘s name: ____________________________________ (please print)

The person who obtains the informed consent discussion must also sign and date this form.

Signature: ____Date ________

Name: ____ (please print)

Signature of witness (if applicable)

Signature of witness: _________________________________Date_________

Witnessed by (print name): _____________________________

ANNEX 2: PaedsQL: Paediatric Quality of Life inventory

ID
#_________________

Date:__________

Age of
Child ______

Sex of the
child: 1=M 2=F

Relation to Child:

1=Mother
2=Father
3=Other (Specify)______________

Sex of
Guardian/Parent: 1=M 2=F

To answered by parents of eligible Children

On the following page a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past one month

0= if it is never a problem
1=if it is almost never a problem
2=If it is sometimes a problem
3=if it is often a problem
4=if it is almost always a problem

In the past **ONE month**, how much of a problem has child had with ….					
	Never 0	Almost never 1	Sometimes 2	Often 3	Almost always 4
Physical FUNCTIONING (*Problems with…)*					
1. Walking few meters (5-10M)					
2. Running					
3. Participating in sports activity or exercise					
4. Lifting something heavy					
5. Doing chores(e.g. Picking up toys/helping at home)					
6. Having hurts/aches or pain					
EMOTIONAL FUNCTIONING(Problems with)					
1. Feeling afraid or scared					
2. Feeling sad					
3. Feeling angry					
4. Trouble sleeping					
5. Worrying about what will happen to him or her					
SOCIAL FUNCTION(Problems with..)					
1. Getting along with other Children					
2. Other children wanting to be his or her friends					
3. Getting teased by other children					
4. Not able to do things that other children his or her age can do					
5. Keeping up when playing with other children					
SCHOOL FUNCTION (Problems with)					
Ask if Child attends School or nursery. If **YES** then proceed to ask the following questions. If **NO**:**END the interview**					
1. Paying attention in class					
2. Forgetting things					
3. Keeping up with School work					
4. Missing school because of not feeling well					
5. Missing school to go to the doctor or hospital					

ANNEX 3: Institutional Self-Assessment Tool (ISAT)

Introduction and Instructions

The Institutional Self-Assessment Tool (ISAT) will be used to assess the hospitals capacity to provide
Family-centered palliative care for children with life threatening diseases.
The tool is divided into two components:

1) **Hospital/Administrative component:** To be filled out by someone in an administrative position who will be able to answer general questions pertinent to hospital-wide issues, and
2) **Unit Level component:** To be filled out by a representative of a local unit

Target Respondents:
The Clinical care specialist of the University teaching Hospital(UTH) and consultant incharge of Palliative care unit

Question Response	
1. For the purpose of this questionnaire, which unit are you representing?	**ID Number:**
2. What is your position and role in the unit?	
3. Number of beds on this unit:	
4. How many children were admitted to this unit in the last year? *(Exclude admissions for less than 24 hours)*	
5. How many children died in this unit in the last year?	
6. Please provide a count for the following professionals devoted solely to care of children in this unit.	
Medical Doctors	
Registered Nurses	
Advance Practice Nurses	
Nurse Practitioners	
Licensed Vocational	
Nurses	
Child Life Specialists	
Social Workers	
Chaplains	
Psychologists	
Physical Therapists	
Occupational Therapists	
Art/Music/Creative	
Therapists	
Hospital-based Teachers	
Grief Counselors.	
Bereavement Specialists..	
Others (please specify)	
_______ _______	
7. Does the unit have dedicated pediatric hospice/palliative care beds?	Yes...... If **Yes**, how many? _____
	No
8. Does the unit have pediatric hospice/palliative care flexible beds?	1. Yes...... If **Yes**, how many? _____
	2. No
9. Is there a procedure to identify children with life-threatening conditions who might benefit from palliative care interventions, so that a palliative care conference can be arranged?	1. Yes
	2. No
	3. Don‘t know
If **Yes**, is the procedure initiated by: (check all that apply)	1. MD recommendation only
	2. Any member of the health care team
	3. Any member of the family
	4. Severity of Symptoms
	5. Severity of illness score
	6. Disability score (if so, which

	one(s))
	7. Relapse/exacerbation of illness
	8. Advance directive status
	9. Length of current hospitalization
	10. Frequency of admission in the last year
	11. Diagnosis at the time a potentially life-threatening condition is identified
	12. Other (please specify)
10. Is palliative care identified as a priority during employee orientation?	1. Yes
	2. No
	3. Don‘t know
11. Is family-centered care identified as a priority during employee orientation?	1. Yes
	2. No
	3. Don‘t know
12. Is there a mechanism to communicate to families institutional readiness to facilitate palliative care (e.g., institutional philosophy, goals, staffing capacity, special programs, and consultation services relevant to palliative care)?	1. Yes
	2. No
	3. Don‘t know
If **Yes**, how is this communicated? (check all that apply)	1. Written admission packet information
	2. Standardized oral orientation information
	3. Educational/informational posters placed prominently
	4. Other (please specify)
Organizational Structures Supporting Palliative Care	
	1. Yes
13. Is there a hospice that provides paediatric care in your local community?	2. No
	3. Don‘t know
If **Yes**, does your hospital have a relationship with them to provide services to your patients?	1. Yes
	2. No
	3. Don‘t know
If **Yes**, is the relationship:	1. Formal (there is a written contract)
	2. Informal
	3. Don‘t know
14. Is there a parent advisory council, or similar formal structure for parent input into the operations of the unit?	1. Yes
	2. No
	3. Don‘t know
15. Is there a paediatric palliative care team available to patients in this unit?	1. Yes
	2. No
	3. Don‘t know
If **Yes**, the palliative care team members include: (check all that apply)	1. Physician
	2. Registered Nurse
	3. Social Worker

	4. Pharmacist
	5. Child Life Specialist
	6. Psychologist
	7. Physical Therapist
	8. Occupational Therapist
	9. Hospital-based K-12 Teacher
	10. Chaplain
	11. Art/Music/Creative Therapist
	12. Other (please specify)
16. Is there a paediatric pain management team available to patients in this unit?	1. Yes
	2. No
	3. Don‘t know
17. Is there an Office of Ethics, Ethics Consultant, and/or Ethics Committee available to patients /families and providers on this unit?	1. Yes
	2. No
	3. Don‘t know
18. Ethics committee or ethics consultation can be initiated by: (check all that apply)	
	1. Attending Physician
	2. Any member of the health care team
	3. Any family member
	4. Don‘t know
	5. No one
	6. Don‘t Know
	7. Other (please specify)
19. . Is there a policy that chronically ill children are assigned a consistent caregiver or care team at each hospital admission?	1. Yes
	2. No
	3. Don‘t Know
20. Do mortality and morbidity conferences include an evaluation of the palliative care delivered to the child and family?	1. Yes
	2. No
	3. Don‘t Know
If **Yes**, are the palliative care issues addressed for: (check one)	1. Every death
	2. Most deaths
	3. Some deaths
	4. None
	5. Don‘t know
Facilities/Space Supporting Palliative Care	
21. On your unit, which of the following facilities are available to families of children with life-threatening conditions? (check all that apply)	
Facility Availability	
a) Suites where the child and family can be together	1. Yes
	2. No
	3. Don‘t Know
b) Sleeping accommodations for parents/family in the child‘s room	
	1. Yes
	2. No
	3. Don‘t Know

c) Sleeping accommodations for parents/family elsewhere in the unit or hospital	1. Yes, in unit 2. Yes, in hospital, outside of unit 3. No 4. Don‘t Know
d) Bathrooms with showers	1. Yes 2. No 3. Don‘t Know
e) Lockers for personal belongings	1. Yes 2. No 3. Don‘t Know
f) Family lounge	1. Yes 2. No 3. Don‘t Know
g) Private room for consultation with health care professionals	1. Yes 2. No 3. Don‘t Know
h) Private room to accommodate the child and family when a child is dying	1. Yes 2. No 3. Don‘t Know
i) Supervised play area for siblings, appropriate for a range of ages	1. Yes 2. No 3. Don‘t Know

Staff/Personnel Supporting Palliative Care

22. Are non-clinical staff / personnel (info desk, housekeeping, valets, food service workers) who interact with children with life-threatening conditions and their families oriented about the importance of family-centered, pediatric palliative care when they begin their positions?	1. Yes 2. No 3. Don‘t Know
If **Yes**, is this orientation periodically updated?	1. Yes 2. No 3. Don‘t Know
23. Are skills needed to provide effective palliative care included in health care provider job descriptions?	1. Yes 2. No 3. Don‘t Know
24. Do health professionals in this unit, who care for children with life-threatening conditions, receive periodic education/training related to family-centered, pediatric palliative care, including the following? (check all that apply)	1. Family-centered approach 2. Ethical issues in paediatrics 3. Legal issues related to pediatric end-of-life care 4. Cultural competency for ethnic and religious groups 5. commonly encountered in local community 6. Communication skills, including active listening, breaking 7. bad news, discussing death and dying

	8. Pain assessment
	9. Non-pain symptom assessment
	10. Pain management
	11. Non-pain symptom management
	12. Bereavement care
	13. Child development stages and issues
	14. Psychological management
	15. Other (please specify)
Needs of the Child in Palliative Care	
Assessment and Identification	
25. Since a child‘s needs vary over time and even within a single hospitalization, is there a procedure or mechanism in place to assure periodic routine assessment of the child‘s needs in the following areas:	
a) Physical Needs (symptom relief, need for physical therapy):	
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
*If **Yes**,a. Do you use developmentally appropriate tools to facilitate the assessment?*	
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
b) Social Needs (perception of relations with others):	
	1. Yes always
	2. Sometimes
	3. No
If **Yes**, Do you use developmentally appropriate tools to facilitate the assessment?	4. Don‘t Know
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
c) Emotional Needs (mood and self-concept):	
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
Do you use developmentally appropriate tools to facilitate the assessment?	
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
d) Spiritual Needs (issues of meaning and value, belief	
	1. Yes always

systems): Do you use developmentally appropriate tools to facilitate the assessment?	2. Sometimes
	3. No
	4. Don‘t Know
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
26. Is someone assigned to routinely assess pain in the patients on your unit?	
	1. Yes always
	2. Sometimes
	3. No
	4. Don‘t Know
If **Yes**, whose responsibility is it?	
	1. Attending Physician
	2. Registered Nurse
	3. Advance Practice Nurse
	4. Don‘t Know
	5. Other (please specify)
27. When doing pain assessments, do the staff use a developmentally appropriate tool, e.g., VAS?	
	1. Yes
	2. Sometimes
	3. No
	4. Don‘t Know
28. Is someone on your unit responsible for routinely documenting the child‘s pain in the medical record?	1. Yes
	2. Sometimes
	3. No
	4. Don‘t Know
If **Yes**, whose responsibility is it?	
	1. Attending Physician
	2. Registered Nurse
	3. Advance Practice Nurse
	4. Don‘t Know
	5. Other (please specify)
29. When pain is documented, is someone responsible for followup and verification that the treatment was provided and was effective?	1. Yes
	2. Sometimes
	3. No
	4. Don‘t Know
	1. Attending Physician
If **Yes**, whose responsibility is it?	2. Registered Nurse
	3. Advance Practice Nurse
	4. Don‘t Know
	5. Other (please specify)
30. Do you have a developmentally appropriate range of tools to assess the severity of these symptoms?	1. Yes
	2. Sometimes
	3. No
	4. Don‘t Know
31. Is there a person whose responsibility it is to assess the severity of these symptoms?	1. Yes
	2. Sometimes

	3. No
	4. Don‘t Know
32. Is there a monitoring process in place to assure the effective resolution of the following symptoms?	
a) Pain	1. Yes
	2. No
	3. Don‘t Know
b) Nausea	1. Yes
	2. No
	3. Don‘t Know
c) Vomiting	1. Yes
/	2. No
	3. Don‘t Know
d) Diarrhoea	1. Yes
	2. No
	3. Don‘t Know
e) Constipation	1. Yes
	2. No
	3. Don‘t Know
Depression	1. Yes
Care Plan	2. No
	3. Don‘t Know
Needs of the Family in Palliative Care	
Assessment and Identification	
33. Is there a standardized mechanism within the unit to assess and implement the preferences of families of children with life-threatening conditions regarding:	1. Yes
	2. No
	3. Don‘t Know
34. Which of the following professionals are routinely involved with the family (parents, siblings, grandparents) of a child with a life-threatening condition:	1. Physician
	2. Registered Nurse
	3. Chaplain
	4. Social worker or mental health professional
	5. Child Life Specialist
	6. Patient representative/advocate
	7. Other (please specify)
35. What triggers prompt referral of the family to pertinent team members? (check all that apply)	1. Family request
	2. Initial diagnosis of the child‘s life-threatening condition
	3. ICU admission
	4. The child‘s need for surgical intervention
	5. Recognition of imminent death by the health care team

	6. Other (please specify)
Communication and Decision-Making	
36. Does a single member of the health care team take responsibility for coordinating communication with a particular family when the child has a life threatening condition?	1. Yes
	2. No
	3. Don‘t Know
37. Are formal meetings between family members and one or more members of the health care team held to discuss goals of care and progress to date?	1. Yes
	2. No
	3. Don‘t Know
If **Yes**, when are these meetings typically held: (check all that apply)	
	1. On admission
	2. Daily or more often
	3. Every other day
	4. Weekly
	5. At discharge
	6. When the child‘s condition worsens
	7. When imminent death is recognized
	8. Other (please specify)
38. Is there a policy or standard stating that families should receive updates about their child‘s condition and treatment?	1. Yes
	2. No
	3. Don‘t Know
If **Yes**, how is the communication accomplished?	
	1. Bedside rounds
	2. Face-to-face meetings
	3. Bedside journal
	4. Telephone call
	5. Secure email
	6. Don‘t know
	7. Other (please specify)
	1.
39. At the time of transfer or discharge, is there a procedure, standard of practice or other mechanism to ensure that families of children with a life threatening condition receive an updated, comprehensive,portable medical record?	2. Yes
	3. No
	4. Don‘t Know
40. Are parents and children routinely provided with printed materials regarding the child‘s condition that are written at an appropriate educational and language level?	1. Yes
	2. No
	3. Don‘t Know
41. Are post-death meetings routinely scheduled with families after death?	1. Yes
	2. No
	3. Don‘t Know
Support and Resources	
42. Are any of the following offered to support the practical and emotional needs of families of children with life threatening conditions?	

a) Practical Needs	
	1. Food
	2. Transport
	3. Financial assistance
	4. Housing for families of children with prolonged hospital stays
	5. Access to long-distance and local telephone service
	6. Other (please specify)
b) Social/Emotional Needs	
	1. Play areas for healthy siblings
	2. Psychological consulting for siblings
	3. Support groups for parents and siblings
	4. Other (please specify)
	5. Don‘t know
c) Spiritual needs	1. Chaplaincy
	2. Spiritual counsellors
	3. Church referrals
	4. Other
43. Does the hospital or unit have a formalized bereavement program?	1. Yes, hospital
	2. Yes, unit
	3. No
	4. Don‘t Know
Care of the Professional Caregivers	

44. Which of the following is the unit doing on a routine basis to ensure the well-being of personnel who care for children living with life-threatening conditions and their families?

	Yes	**No**
1) Providing paid time and relief of clinical duties to attend	1	2
2) patients‘ funerals/visitations/memorials	1	2
3) Providing an atmosphere of respect for all disciplines	1	2
4) Providing mentors	1	2
5) Sending condolence cards to personnel who were extensively involved with a patient who has died	1	2
6) Providing flexibility in scheduling to accommodate personnel grieving after the loss of a patient	1	2
7) Providing effective education on palliative care topics	1	2
8) Individual counseling	1	2
9) Employee assistance office	1	2
10) Group counseling/support meetings	1	2
11) Encouraging open communication/exchange of views among all disciplines involved in the child‘s care	1	2
12) Providing self-care opportunities on the unit such as,massage,music etc	11	2
13) Opportunities to discuss troubling cases, for example:	1	2

Thank you for your effort in answering these questions

ANNEX 4: Focus Group Discussion Guide for parents/Guardians

This study guide aims to elicit information from families affected by cancer. The target group are parents or guardians with a child who has a life limiting illness. The specific areas of probing will include the following questions:

1. What are the patient's needs and do they think that they are being met by the specialist palliative care team?
2. What are the needs of the families/carers and do they think that they are being met?
3. What do the families/carers see as the needs of their family member who requires palliative care for cancer, and do they think that they are being met?
4. If these needs are not being met, what are the interventions that are needed to give the patient and their carers/families a satisfactory quality of life

In order to provide a general guide about the above areas of information collection we have sub divided the guide into specific questions with additional probes

Question 1: What are problems with your children?

(List all the problems mentioned by participants and   guiding respondents to focus on problems related to the care of the children)

Probe : *Have the doctors discussed with you the diagnosis?*

Question 2: *What are some of the problems affecting your child right now?*
(Probe for pain, appetite, weight loss)

Question 3:   For the listed problems kindly tell me what help you have received to address your child's problems

Question 4: Have you heard of the word palliative care? If so what do you understand?

(The interviewer will need to translate the concept of 'palliative care' – emphasise its similarity/difference from terminal care). (**GIVE PARENTS/GUARDIAN A DEFINITION OF PALLIATIVE CARE IF NO APPROPRIATE RESPONSE GIVE)**

Question 5: Tell me about your experiences of palliative care

Probe: Could you relate your experiences since diagnosis with cancer (i.e. did it affect you, family member, friend, etc)

Prompt: How did you feel about your child having cancer?

Question 6: Do you know what services are involved in the cancer care/treatment?

Prompt: If you (or family member) were looked after by professional cancer services, what role/services did they provide?

Probe: Received physical and psychosocial, Spiritual support?

Prompt: *What was your children's (or family member) experience of these services?*

Probe: Could you relate your experiences: i.e. Role of staff/sensitive to needs/food/need to

pray/admission of Visitors/communication with staff

What were your thoughts about the service? (Physical ,psychological, spiritual care)

How easy is it to access the palliative care services?

Question 7: How satisfied are you with the care and support that you are getting at the moment?

Probe: How well do the palliative care services meet your needs?

NEEDS OF PATIENT/FAMILY MEMBERS/CARER

Question 8: What are the needs that you feel the palliative care services can help with?

Probe: For the child and the family

Probe:
-Treatment?
-Physical care?
- Psychosocial care?
- Emotional/spiritual?
- Financial?
- Information?
- Any Other?

Prompt: How well do you think that the palliative care services are meeting these needs? (after each of above sections)

CHANGES REQUIRED BY PATIENT/FAMILY MEMBER/CARER

Question 9: What can the palliative care services do you want to help meet your needs?

Note: Refer to the list of palliative care needs mentioned above

Question 10: For palliative care services, which language would you find most useful to receive information in?

Probe: Aware of any translated material? posters? leaflets? videos? audio cassettes?

We have come to the end of the interview. Thank you for your time.

ANNEX 5: Focus Group Discussion guide for Health workers

This interview guide will be used to collect information from Health workers who serve children with life limiting illness.

.

Time: 1 hour

Objectives: To describe Palliative Care services and explore Palliative Care needs for children with life limiting illness and attending the University teaching hospital in Lusaka

Materials

- Flip chart
- Tape recorder
- Markers
- Sticky stuff
- Facilitator note book
- Pens

Preparations

- Suitable Venue within the community
- All materials laid out and ready for use
- Drinks and snacks for the participants and facilitator
- One facilitator should record the following details for each participant: Name, age, sex, marital status, source of income, number of children and length of stay in area

Introduction

(Self introduction by facilitator)

We have selected you to take part in this interview because you work with children who have life limiting illness. We would like to learn about your experience in working with such children and their families in providing palliative care services. We would like to find out what services are available and those that are needed to provide care for children and families facing life limiting illness

Your participation in the focus group discussion is voluntary. You will be free to decline if you wish. If you agree to participate, you can decide not to answer certain questions and leave the discussion at any time. If you agree you will be asked to sign this consent form. Your names and any other personal information you give us will be kept confidential. The results of this research may be published but your identity will be kept confidential. Your participation or non participation will not affect your work to at the health hospital.

There is no financial benefit for your participation, but we do value your opinions and the study help improve palliative care for sick children and their families. You are free to ask any questions before you sign the consent form and after the discussion.

Basic knowledge about Palliative Care

1. What do you understand by the word Palliative Care?

   (Probe for Adult and Children's definition of palliative Care)
2. What is involved in providing Palliative care?
   (Probe for components: Physical, psychosocial and spiritual)

3. What is special about Children's palliative care services?

Palliative Care services

4. Do you provide Palliative care for children in this hospital?
   (Probe for type of services provided and the target groups)

5. Do you have wards that provide Palliative care?

   (Probe for type of patients that are seen and the common diagnosis)
6. Do you have doctors or nurses that have been trained in palliative care?
   (Probe for number trained and when training was done)

7. Do you have a palliative care team at this hospital?
   (Probe for composition and roles)

8. How do you identify children with Palliative Care needs?
   (Probe for systematic or random identification of such needs)

9. How are referral do for such children to the palliative care team if it exists?

Common Palliative care needs

10. What are the major palliative care needs for most children with life limiting illnesses
    (Probe for Cancer and HIV specifically)

11. Is pain a major problem among children with chronic illness in this hospital?
    (Probe for tools used to assess pain and Morphine availability)

Family Centred Care

12. What are the common challenges that families with chronically ill children face when admitted to this hospital?
13. What help is available to support such families? And who coordinates this?
14. How do you provide information about the diagnosis and prognosis to the child and family
    (Probe for the place, time and who provides such information)
15. What kind of material support do families get?
    (Probe: Financial, Transport and accommodation)
16. What kind of psychological support do families receive?
    (Probe for available of psychosocial counsellors and psychiatrist)

17. What kind of spiritual support do families and children receive?
    (Probe for Chaplaincy and Church Referrals)

18. Do you provide any bereavement support to families?
    (If So How is this arranged?
19. Do you provide and memorial events?

20. Can you suggest ways in which palliative care can be improved for children in this hospital?

    (Probe for Human resources and training, Infrastructure and other resources)

ANNEX 6: Distress protocol

The *Distress Protocol will mainly cover issues of* data collection for participants bearing in mind that these are a vulnerable group and they find themselves in hospital setting where their freedom is further restricted by both their child ill health and unfamiliar environment. In this study the distress protocol is as follows.

All the study participates will be provided with information about the study. All eligible children and their guardians will be asked to provide written consent for guardians and assent for children.
The data collection will take place in a quiet office space or nearby garden.
The interviewers will be trained on how to identify participants who may become distressed during the interview. When this is noticed, the interviewer will stop the interview and establish if it is possible to settle the distressed participant. If the participant does not settle down after a short break, he/she will be offered counselling by the research team. If participants voluntarily want to come back to continue the interview, the interview will be continued at a time agreeable to the participant.

If longer term counselling is required, referral to hospital counselling services will be arranged with the participant‘s consent.
As with research data, all information will be treated as confidential except in the situation of the patient‘s or family‘s safety being at risk, in which case the information may be acted upon.

ANNEX 7: NEQ – Needs Evaluation Questionnaire:

(Translated from original in Italian made available by Dr Tamburini)

On Admission

ID number: ____

Ward

____

Room No. ____________ ID No.* ____________ Hospital No.*____________

Date of completion /_/_/ /_/_/ /_/_/

Dear Sir/Madam

The following questionnaire lists a variety of needs, linked to the condition of one‘s health, which people have said they have had* We ask that you answer **YES** ,for the need that you consider that you and your child have **at this moment**, and **NO** for the need that you think you do not have*

YES NO

	Yes	No
—I need more information about the child‘s diagnosis”	1	2
—I need more information about my child‘s future condition”	1	2
—I need more information about the examination done to my child”	1	2
—I need more explanations about the child‘s treatments”	1	2
—I need to be more involved in the therapeutic choices of my child”	1	2
—I need clinicians and nurses to give me more comprehensible	1	2
information”	1	2
—I need clinicians to be more sincere with me about the child‘s illness”	1	2
—I need to have a better dialogue with clinicians”	1	2
—I need the child‘s symptoms (pain, nausea, insomnia, etc.) to be better controlled”	1	2
—The child needs more help with eating, dressing, and going to the bathroom”	1	2
—I need better respect for our privacy”	1	2
—I need better attention from nurses”	1	2
—I need to be more reassured by the clinicians”	1	2
—I need better services from the hospital (bathrooms, meals, cleaning)”	1	2
—I need to have more economic-insurance information (tickets,	1	2
invalidity, etc.) In relation to my illness”	1	2
—I need economic help in caring for my child”	1	2
—The child needs to see a psychologist our counsellor ”	1	2
—The child needs to see a spiritual counsellor or priest”	1	2
—I need child needs to speak with people who have this same experience”	1	2
—I need to be more reassured by my relatives”	1	2
—I need to feel more useful within my family”	1	2
—I need to feel less abandoned”	1	2
—I need to receive less commiseration from other people”	1	2
Other: ____		
At this moment, my foremost need is: __________________________		

____

ANNEX 8: Information shared with eligible children.(Verbal assent)

We are asking your parent (mother/father/legal guardian) to take part in a study to find out needs of children and their families who are affected by Cancer or HIV infection. We will be carrying out this study at the University teaching hospital which is our main referral hospital in Zambia. We would like to make sure that you are aware about this study and that you are happy for your parent(s) (legal guardian) to share information about your illness. We want you to know the purpose of the research, the possible risks and benefits. We have provided similar information to your parents/legal guardian who will sign the consent agreeing to take part in the study.

Who is doing the study?

This study is being performed by Dr.Wilbroad Mutale with support from the Palliative Care Association of Zambia and the Ministry of Health.
The full contact address for the principal Investigator Dr.Wilbroad Mutale is:
University of Zambia School of Medicine
P.O Box 50110, Lusaka:
Phone: +260979322831
Email: wmutale@yahoo.com

What is the purpose of the study?

The study involves mainly asking questions about the experience of children and their families with chronic illness especially cancer and HIV infection. We would like to know what special needs these children and their families have in order to guide provision of better care for the affected children and their families. You are one of the children with chronic illness so we would like to learn from your experience and that of your family.

What is the benefit to you of taking part in this study?

There may be no direct benefit to you from this survey. However, information learned from this study could be used to improve services for children and families suffering from chronic illness in Zambia. We still do not know what special needs these children and their families require so when your (parent or guardian) takes part they will be helping us to find out what these needs are and how best to provide help.

What are the Risks, Stresses and Discomfort of taking part in this study?

Risks of participating in this study and answering the questionnaire are minimal.

Confidentiality of information and privacy of the participant

All personal information obtained during this study will be kept strictly confidential. The answers will be entered in a computer, but your name will not be included, and you will be identified by a coded number only.

Withdrawal without Prejudice

Please be informed that your parent/legal guardian may withdraw their participation at any time without penalty. Their refusal will not affect access or quality of health services here at UTH or elsewhere for you and your parents/legal guardian

Costs to You

There will be no financial cost to you or your family for participating in the questionnaire.

Who is signing on your behalf

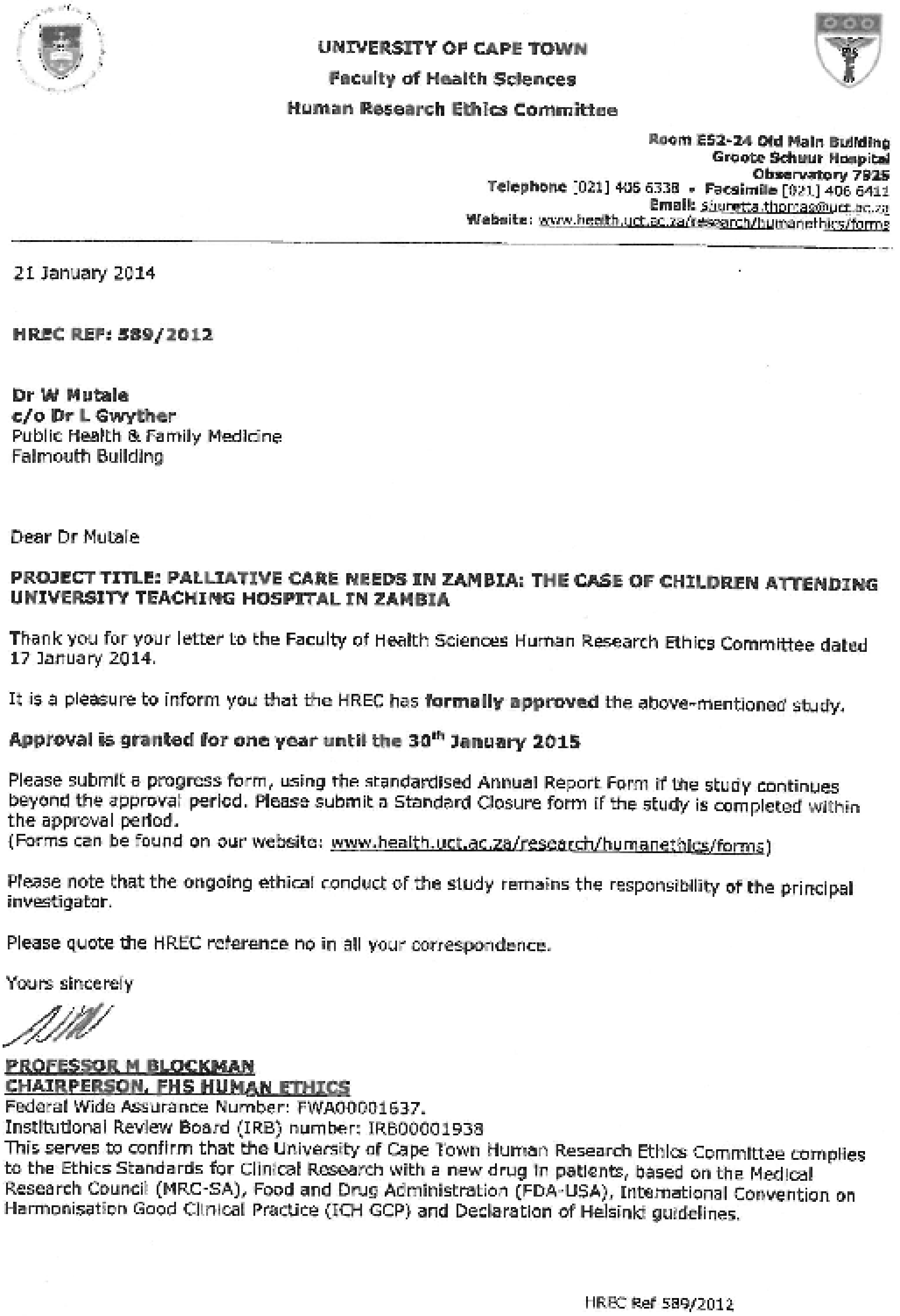
Your parents/legal guardian will sign the consent form. However, we are interest in making sure that you are also happy for your parents/legal guardian to take part in this study.

Thank your time. If you have any questions, please ask them now. I will be pleased to answer them.

Are you happy for your parents/legal guardian to take part in the study? (Circle appropriate)

Yes
No

Witness signature/Thumb print:



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/research/humanethics/forms

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21 January 2014

HREC REF: 589/2012

Dr W Mutale
c/o Dr L Gwyther
Public Health & Family Medicine
Falmouth Building

Dear Dr Mutale

PROJECT TITLE: PALLIATIVE CARE NEEDS IN ZAMBIA: THE CASE OF CHILDREN ATTENDING UNIVERSITY TEACHING HOSPITAL IN ZAMBIA

Thank you for your letter to the Faculty of Health Sciences Human Research Ethics Committee dated 17 January 2014.

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

Approval is granted for one year until the 30th January 2015

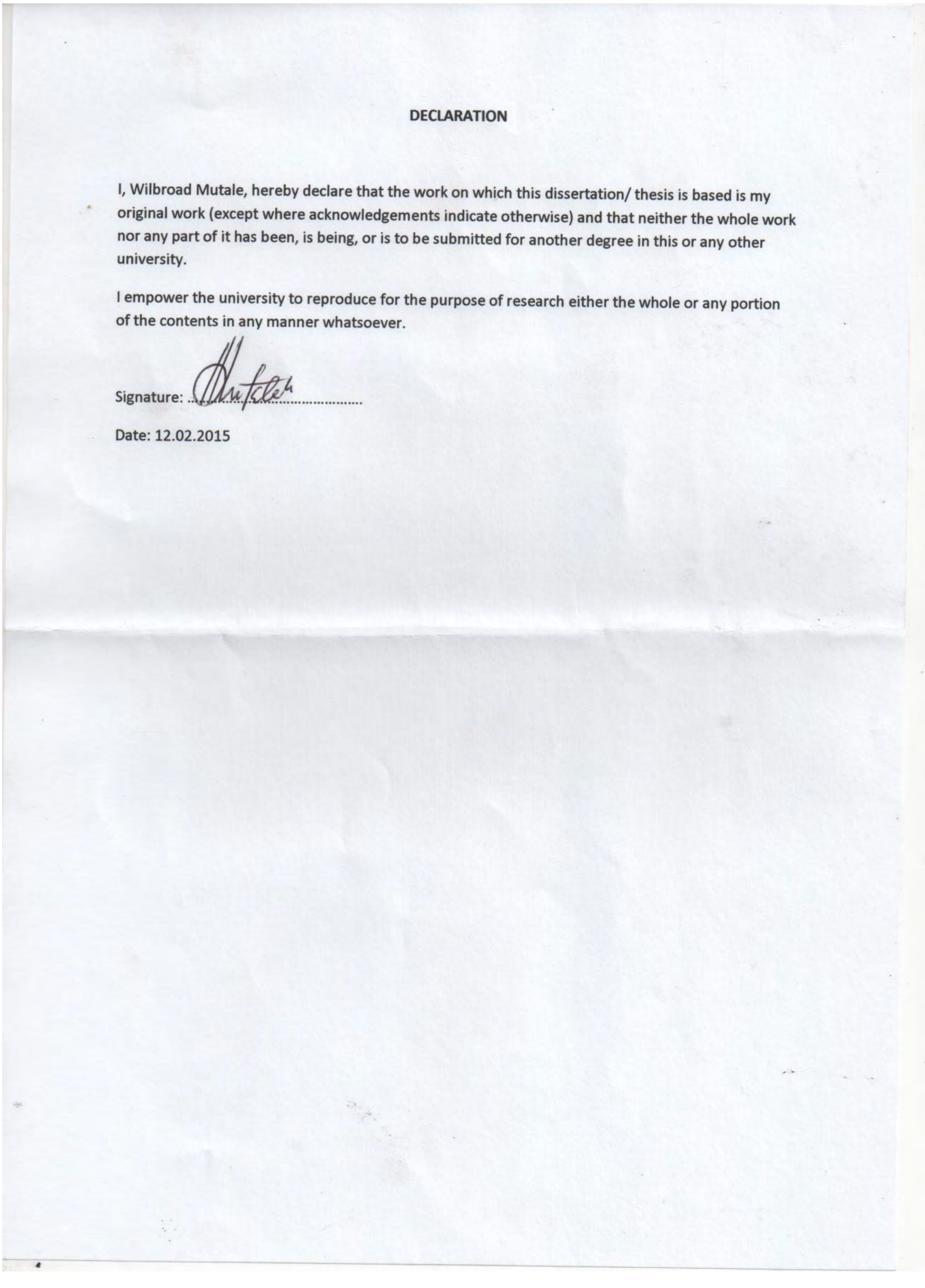
Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

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

Please quote the HREC reference no in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.



DECLARATION

I, Wilbroad Mutale, hereby declare that the work on which this dissertation/ thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: ....

Date: 12.02.2015