

**DECISION-MAKING APPROACHES IN CHILDREN'S PALLIATIVE  
CARE INSTITUTIONS: A CASE STUDY OF HOSPICE AFRICA  
UGANDA.**

**BY**

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## **DECLARATION**

I declare that this is my original piece of work and I remain responsible for any errors, omissions and commissions here in.

It has not been submitted for a degree in any other university.

Signed:\_\_\_\_\_Date:\_\_\_\_\_

**Nimungu Alfred Duku**

This dissertation report has been submitted to Makerere University School of Graduate Studies with my approval and authority as a university supervisor.

Signed:\_\_\_\_\_Date:\_\_\_\_\_

**Paul Bukuluki Wako (PhD)**

Supervisor

## **DEDICATION**

This book is dedicated to my wife: Mrs Nimungu Lillian Ogen for her inspiration and support during this study.

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Alfred Nimungu Duku

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## **DEFINITION OF KEY CONCEPTS**

**Palliative care** – Refers to Care provided for people of all ages who have life-limiting illnesses, with little or no prospect of cure, and for whom the primary treatment goal is quality of life. Palliative care integrates physical, psychological, emotional, and spiritual care for patients, their families, and other carers (WHO, 1998).

**Children's palliative care:** Children's palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.

**Life-limiting Conditions:** Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die e.g Cancer and HIV/AIDS. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

**Carers** – This refers to family carers who provide unpaid, informal care to the patient. Whilst some family carers may be eligible for benefits such as house maids, this definition excludes those that are actually employed as carers.



## **LIST OF ACRONYMS**

AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral Drugs
ATIC	AIDS Treatment Information Centre
CPCC	Clinical Palliative Care Course
CVW	Community Volunteer Workers
GoU	Government of Uganda
HAU	Hospice Africa Uganda
HIV	Human Immunodeficiency Virus
HSSP	Health Sector Strategic Plan
LHH	Little Hospice Hoima
MHM	Mobile Hospice Mbarara
MoH	Ministry of Health
NGO	Non-Governmental Organization
PC	Palliative Care
PCAU	Palliative Care Association of Uganda
PEPFAR	President Bush's Emergency Plan for AIDS Relief (Emergency Fund)
UAC	Uganda AIDS Commission
USAID	United States Agency for International Development
WHO	World Health Organization

## **ABSTRACT**

This study aimed at exploring decision-making approaches in children palliative care institutions and was a case study of Hospice Africa Uganda. The exploration centred on: meanings and experiences with decision-making, participants in decision-making, ethical principles used in decision-making, factors that influence decision-making and challenges in decision-making in children's palliative care.

Qualitative methodology was adopted for the study. The sample was purposively selected and included palliative care practitioners, children on hospice programme, and family carers of children on programme. Data were collected using in-depth, key informant interviews and focus group discussions. Content and thematic analysis was done. Verbatim statements were used to present data and implications were drawn from them in the context of the study.

Study findings reveal the fact that children are not just little adults. Children and adults are at different levels of cognitive, intellectual and emotional development. Decision-making is perceived as a multi stakeholder responsibility, involving health workers, children, family carers, non health professionals etc. Ethical dilemma is common in areas such as knowing whose view matters in the course of decision-making in children palliative care. Social and cultural issues such as family power relations, gender differences and attitudes of palliative care practitioners greatly determine the use and relevancy of some of the ethical principles.

In conclusion, experiences and approaches to decision-making in children's palliative care vary from individual to individual and location to location. Decision-making in children's palliative care is best done in partnership, involving multiple stakeholders- health and non- health workers. Ethical principles that provide guidance in the care of adults are insufficient in the context of caring for children. Issues related to consent, disclosure of information, capacity assessment, treatment decisions, and bereavement are more complex in children's palliative care.

# CHAPTER ONE

## 1.1 Background to the study

Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual (WHO 2002). Palliative care provides both pain and symptom control to patients with incurable, life limiting diseases and offers psychological support to the patients and their families from a point of diagnosis until the end of life is reached to include bereavement (Harding, 2003).

Children's palliative care embraces the concurrent administration of curative and supportive care with attention to physical, psychosocial, and spiritual pain. Such comprehensive care requires input from a multidisciplinary team that includes physicians, nurses, social workers, religious leaders, child counselors, pharmacists, and physical/occupational therapists. Children's Palliative Care aims to improve the quality of life for these children when a curative treatment is no longer an option, through physical, emotional, financial, social and spiritual support; including provision of morphine and other palliative medication (WHO, 2003).

There has been documented increase in childhood cancers in Uganda since 1990. In 1997, Uganda had the highest age-standardised rate of childhood Kaposi Sarcoma (KS) in the world at 70.2 cases per million (Uganda AIDS Commission, 2004). This reflects the impact that HIV has had on childhood cancers in Uganda. It is anticipated that with the rollout of ART programme and increased awareness of childhood cancers in the informal health sector, the demand for palliative care services for children will increase (HAU Strategic Plan, 2006-2011)

Children's palliative care in Africa and in Uganda in particular is a much needed service but unfortunately, it is an extremely new field. Much as Hospice Africa Uganda has been offering palliative care services since 1993, children's palliative care remains a new domain for the

palliative care team at HAU. It is important also to realize that the needs of children with life-limiting illnesses are significantly different to those of adults, and therefore require different management approaches.

In Africa more than 400,000 children under 15 died of AIDS in 2003. There are over 13 million orphans who have lost one or both parents to AIDS. Each year there are approximately 166,000 children under 15 diagnosed with cancer world wide. 84% of these are diagnosed in developing countries. Each year there are at least 80,000 deaths from cancer in children under 15 years, 90% of the deaths occur in developing countries. Around 80% of children dying in Africa die at home without seeing a health care provider (WHO, 2003).

Children's palliative care presents a huge challenge. Health and non health professionals often have to manage with fewer physical and human resources, logistical issues act as barriers to care. Children's rights are a live issue in Africa, and issues of child's consent and child protection in most cases is overlooked in palliative care (Amery, 2009).

Despite the laudable success recorded in improving access to palliative care services in Uganda, provision of children's palliative care is patchy and the structure of specialist teams variable. Thousands of children in Uganda die with cancer and HIV/AIDS in pain and distress for lack of access to children's palliative care services.

## **1.2 Statement of the problem**

Decision-making in children's palliative care is key dilemma for both health and non health palliative care service providers. In children's palliative care, the inherent dilemma of decision-making is compounded by socio cultural diversity, uncertainty in the effects of the ill health conditions, and complex symptom in children's illnesses, among others.

The meaning of decision-making and carer's experiences with decision-making is not documented within existing children's palliative care institutions in Uganda. Much as palliative care is provided based on ethical standards, the definition of standards such as the "best interest" seem not to come out clearly in the existing literature. What may be best to a health worker or a family carer may not necessarily be in the best interest of a child! Major factors that influence children's palliative care decision-making processes are not adequately explained, especially in regards to the welfare of the child in the context of African societies where the "the child is mostly seen but not heard".

The philosophy of multi disciplinary team approach to children's palliative care is ideal but the intricacies involved and the challenges it presents are not clearly presented in existing literature.

## **1.3 Objectives of the study**

### **1.3.1 General objective**

To explore approaches used in decision-making in children's palliative care by critically analyzing the meaning of decision-making, relevant ethical principles, factors that influence decision-making, challenges and key participants in decision-making.

## **1.4 Research questions**

1. What are the meanings and experiences with decision-making in children's palliative care?
2. Who are the major participants (stakeholders) in children's palliative care decision-making?

3. What ethical principles guide's children's palliative care decision-making practices at Hospice Africa Uganda?
4. What factors influence decision-making in children's palliative care?
5. What are the major challenges in decision-making in children's palliative care?

## **1.5 Justification of the study**

Palliative care research and knowledge building is still at inception stage in Uganda. A clear understanding of holistic care, end of life and palliative care ethical issues can best be achieved through research. Through research we can measure direct benefits of palliative care to patients such as improved pain and symptoms, communication, spiritual issues.

So far no study has been undertaken within Hospice Africa Uganda specifically to explore approaches in providing palliative care for children with limited decision-making capacities. And yet good decision-making greatly influence the quality of care given to the affected children and their families.

This study offers policy recommendations for better children's palliative care service planning and implementation. The proposed study contributes knowledge and literature on appropriate approaches to providing palliative care for children with limited capacities to decide. The children's palliative care project at Hospice Africa Uganda will find the results of this study helpful in informing planning and practice of professionals involved in providing care for children affected by life limiting illnesses.

## **1.6 Scope of the study**

The study was limited to existing Hospice Africa Uganda sites ( Kampala, Mbarara and Hoima). This study focused on children between the age of 6-17 years who in principle are expected to meaningfully contribute to decision-making. Almost all the children on hospice programme are in the age range of 6-17 years. The chances of long survival of children below 5 years of age is relatively low due to chronic nature of the illnesses. The research questions, objectives and

problem statement guided the investigations. The research was conducted between August 2008 to October 2009, including research proposal preparation and report writing.

## **1.7 Theoretical framework**

The study was guided by *Palliative care Ethical Decision-making Theory* propounded by Jonsen AR et al, (2002). The theory advocates for consensus based decision-making, involving all stakeholders involved in providing palliative care for patients and families. To the proponents of the theory, consensus based decision-making is a result of logical analysis of the situation, justice and democracy among the stakeholders. On the contrary, Webb P (2005) argued that the extent to which justice and democracy can be operational in hierarchical hospital settings is subject to discussions. She noted that most medical decisions tend to be autocratic; “the doctor knows it best”. However, Webb P (2005) also acknowledges the special role multi professionals play in palliative care decision-making. According to Webb each multi professional team member has a unique contribution. She elaborates that multi professional team have a high capacity of making balanced decisions and benefit from synergies arising from interactions between various members of the team. According to the proponents of the theory, carers are expected to fulfill ethical obligations to benefit patients while minimizing harm. Patients on the other hand are expected to exercise their autonomy by either choosing the palliative care options or refusing it. Roger, (2005) argued that whilst it is understood that autonomy is a basic right that competent patients deserve to have respected, questions arise in terms of how far it extends in end of life situations.

Coleman, (2001) asserts that family members may have opposing views, especially in times of crisis. This may bring about conflict when making palliative care decisions and discussing treatment goals. In Coleman’s view , the theory does not present the strategy to ensure palliative decisions care are made in the best interest of the affected child, especially in situations where a child is unable to express his or her wishes and values. Worthington R (2003) also argues that not everyone believes in benefits of team decision-making, some health workers are more independent minded.

## CHAPTER TWO

### 2 LITERATURE REVIEW

#### 2.1 Introduction:

In this literature review chapter, the status of children's palliative care services is presented. I also discuss the specific research questions of this study, with reference to studies carried out by other scholars.

#### 2.2 *Status of children's Palliative care in Uganda*

Children's Palliative care is a relatively new specialty within Uganda. Clinical services were first introduced into the country in 1993 when Hospice Africa Uganda (HAU) was established (Merriman, 2002). At that time palliative care was absent in most sub-Saharan African countries. Despite the introduction palliative care in Uganda in 1993, children's palliative care has not been given a special priority in Uganda. Hospice Africa Uganda since 1993 has cared for 14,074 patients affected by cancer and or HIV/AIDS (HAU Fact Sheet, August, 2009) . Currently 132 HIV & AIDS infected children are on HAU programme across the 3 sites and the number of new referrals continues to rise rapidly. The incidence of cancer is increasing as the threat from other diseases decreases, due to the additional burden of HIV associated cancers (Hospice Africa Uganda, 2008).

#### 2.3 *Ethical Principles for children's palliative care decision-making:*

Palliative care decisions making for children, like any other health care decision is based on sound consideration of the relevant ethical principles. Children's palliative care advocates such as Jonsen et al (2002), Symonides J (2003), Steinhauser et al (2000), Amery (2009) recommend practice based on the ethical principle of Beneficence - "Best Interest". For the majority of children, health professionals, parents or substitute decision makers are required to make decisions in the best interest of the affected child, taking into consideration the wishes and aspirations of the child, if expressed (Fleischman et al, 1994). According to Amery, (2009)



Clinicians play important roles in helping parents and others with the task of decision-making. He advises that decisions in Children's palliative care should be made through collaboration and consensus building. The goal of decision-making in Campbell et al (2001) is to combine clinician's knowledge and experience with the understanding, values, beliefs and expectations of the patient and parents to achieve optimum outcome of palliative care. Palliative care service providers, parents and carers are responsible for ensuring decisions are made in the best interest of the child patient.

Webb (2005) observes the role professional training in children's palliative care play in application of the critical ethical principle such as beneficence. According to Webb the views expressed above are more of an ideal scenario. Depending on the professional training background, very few health professionals may value the idea of consultative decision-making (Steinhauser et al, 2000). Others may consider this as a bureaucratic process that may greatly delay the process of care and treatment. In the context of Uganda, the family members or carers look up to health professionals to make the best palliative care decisions. Carers expect the health workers to provide the best quality care.

Much as it is important to make decision in the best interest of the affected child, there is no universally agreed definition of "best interest". The concept of "best Interest" is not clearly defined in this literature and it's interpretation may vary, depending on the prevailing circumstances and the person defining it. Moreover in some instances stakeholders may fail to arrive at a consensus regarding best interest for many reasons. In deciding what is in the child's best interests, most health workers try to calculate the consequences of the various decisions and treatment options available and to choose the one that is likely to do the least harm and most good to the child (Amery, 2009).

Autonomy is another major ethical issue in children's palliative care. In general, an individual's right to make decisions is legislated on the basis of age or life experience (Roger, 2005). According to Alderson & Goodey (1998), Bridson et al, (2003), Corner J (1997), respect for autonomy highly depends on the level of competence or capacity, rather than age or life experiences. If the affected child is able to understand the effect of the proposed decision and it's

consequences then he/she is considered competent and capable of making decisions. Roger, (2005) suggests health workers should guide patients in making the right decision provided it is in the best interest of the patient. He argues that autonomy should be exercised within limits, especially for patients with limited capacity to decide and at the stage of end of life. Likewise, Mayberry et al, (2002) emphasizes the need to practice autonomy with clear understanding of the likely consequences of the palliative care decision. It is therefore important to carefully evaluate the patient's capacity to make decision and ensure that decisions are made in the best interest of the patient (Committee on Bioethics-American Academy of pediatrics, 1995).

Capacity to make decisions may change with time depending on the physical, cognitive and emotional effects of illness on the child and with the nature of decisions being made (Amery, 2009). So far the literature reviewed do not clearly suggest how best to ensure values and aspirations of a child with no decision-making capacity is adequately taken care of. In this regard, consensus based approach to decision-making may be relatively applied.

Apart from Steinhäuser et al, (2000) and Amery (2009), most of the literature reviewed do not clearly discuss the influence of socio cultural factors on practice of autonomy and children's participation in decision-making. In the context of most African societies, children are culturally known not to actively contribute to decision-making process except in affluent family set ups or emancipated children, who are mostly in urban settings. Depending on the level of exposure of the palliative care service providers, the affected child may not get adequate opportunities to contribute to decision-making process.

#### **2.4 *Key participants in decision-making in children's palliative care service.***

Jonsen et al (2002), present family centered care as a core value in children's palliative care. When critical illness occurs to a child, the family is intimately affected and challenged. According to Amery (2009) when such illness is life threatening, the family's core values, relationships and emotions are exposed and stretched to the limits. One of the primary purposes of the family is to raise healthy children and to protect them from danger or discomfort. When a family's ability to fulfill these is eroded by illness, their sense of control and justice can be deeply disrupted (Webb, 2005).

Symonides J (2003), Levetown (2004) and Levetown et al (1998) further elaborate that all children need support, love and resources of their families. For the ill child one key resource is the family's involvement in decision-making (Hynson et al, 2003).

According to Goldman & Baum (1994), If the family is in turmoil, feeling out of control or emotionally exhausted they are less likely to participate effectively in decision-making. In this regard palliative care becomes inevitable for the family members as well. Decision-making has been associated with increased sense of control and healthier grieving in some families. Some prefer relinquishing decision-making to health care team. While some clinicians minimize family involvement in decision-making in a bid to avoid burdening the family members (Webb, 2005).

Regarding the child's involvement, Amery (2009), Richard & Jassal (2006) reported great variation in a child's ability to participate in decision-making. Many critically ill children are either too young or incapacitated to participate in palliative care decision (Goldman & Baum, 1994, p. 107-14). As discussed earlier, parents or carers may have to make decisions on behalf of the affected child. However, children who have the ability to express their wishes despite the severity of the illness should be allowed to do so. This demonstrates respect for the child's individuality and is essential for ethical decision-making, providing high quality care, ensuring mutual understanding and addressing differences in opinions before they become basis for conflicts. Depending on the cultural influences and socialization, active participation of children in decision-making may not be absolute (Steinhauser et al, 2000).

According to Amery, (2009) experience of chronic illness may retard the child's cognitive ability but on another hand may increase a child's knowledge about given health conditions. Some parents, Webb (2005) observed that parents may wish to protect their children by not informing them about their ill health finding and prospects and treatment options. Some people believe that children are not able to express themselves or make decisions (Amery, 2009). On the other hand Jonsen et al (2002) noted that some children may not express their concerns or expectations for fear of hurting their parents/ carers feelings.

Nabukeera et al (2007) assert that each child is part of a family unit and decisions about that child must be made within that context. Hsiao (2007) highlights the fact that health professionals may not know exactly how this could be achieved especially when the wishes of the patient and the family are not the same. Whether or not a child is capable of making decisions, he/she should be involved as much as possible and in a developmentally appropriate manner (Carnevale, 1996: 491-503)

Health care team involvement was emphasized by Jonsen et al (2002), Symonides J (2003), Steinhauser et al (2000), Amery (2009). Within the context of palliative care decision-making, there are a variety of roles that may need to be fulfilled by health and non health professionals. These include providing education about available options, problem-solving, emotional and spiritual support and counselling, and conflict mediation. Such a team may include health professionals (nurses, clinicians, pharmacists), social workers, spiritual care providers, and volunteers.

These primary caregivers may consult with specialists in pediatrics, palliative care, and/or other areas but the continuity of care, ready accessibility, and emotional support that they can provide is extremely valuable. This method of providing care requires excellent collaborative and coordinated interdisciplinary work (Hynson, 2001). According to Harding et al (2003), the attitudes and behavior of the members of this team during decision-making can greatly influence both the quality of care provided to the dying patient, and the coping and grieving processes of the family. Collaborative work can become difficult when there are differences of opinion amongst the involved professionals concerning the patient's prognosis, treatment options, and/or the ethical nature of decisions being taken (Webb, 2005). Clinicians can have markedly different attitudes concerning the appropriate intervention for a given patient. Their attitudes and practices concerning end-of-life care, and their comfort level with providing such care, may vary with their country of origin, their age, the length of their professional experience, the seniority of their professional position (Clayton, 2008). Campbell et al (2001) advise health professionals to make a conscious effort to identify and consider how their values influence their perspectives on what is the "right" choice in a given situation. Dealing with differences of opinion requires excellent communication and consensus-building skills.

## **2.5 *Major challenges in decision-making in children's palliative care***

In reports by Levetown, (1998, p.1107-17) and Hynson, (2001, p.323-5), Palliative care decisions for children present a wide range of challenges. Some of the challenges may be similar to those experienced in providing palliative care to adults while others are specific to children affected life limiting illnesses. Children suffer from a number of life limiting diseases, each of which has unique trajectory, treatment options and decision-making points. The duration, type and intensity of care provided varies tremendously between patients and within the same patients at different times of the illnesses (Campbell, 2001, p.117-28). The huge variation in care requirements and high level of uncertainty can make it difficult for health professionals to raise the issue of palliative care options and add to the difficulty of making decisions about these options (Fleischman, 2001)

According to Carnvale (1996), when an adult is seriously ill, the patient and the family may accept the approach of death and reflect on the person's achievements and the fact that they lived a "full" life. When the patient is a child and death is imminent, hope for full life can remain prominent. The death of a child is considered much less "natural" than that of an adult and one of the worst experiences of a family.

Due to various reasons and factors most children in Africa may not actively participate in decisions regarding their treatment (Amery, 2009). Substitute decision makers, usually the child's parents are required. This however does not relieve health professionals of all the responsibilities of decision-making. Optimally the clinician's knowledge, experience and relative objectivity should be combined with values, beliefs and expectations of the parents and the child where relevant to achieve optimum outcome for the child patient (Clayton, 2008; Nabukeera et al, 2007).

Mayberry (2002) recommends that seriously ill children be offered specialized care. She highlights the fact that children also have different social, psychological and developmental differences compared to adults that influence management. The requirements for specialized care can create difficulty for patients, families and health professionals as the required skills set is often not available locally.

## **2.6 Major Gaps in the Literature reviewed**

On the basis of the above literature, the following gaps are noticeable and are therefore key motivation for further research;

From the literature above, the definition of the “best interest” of the affected child is left at the discretion of the person interpreting it. What may be best to a health worker or a family carer may not necessarily be in the best interest of a child! The researcher is therefore highly motivated to establish the best strategy to facilitate consensus based decision-making and how best to ensure palliative care decisions are made in the best interest of the affected child, especially in situations where a child is unable to express his or her wishes and values.

The literature does not adequately explain the major factors that influence decision-making processes, especially in regards to the welfare of the child in the context of African societies where the “the child is mostly seen but not heard”. The influences of socio cultural factors are not explicitly discussed in the literature reviewed.

Ways of minimizing conflicts in the process of children’s palliative care decision-making, especially in situation where the different actors are failing to arrive at a consensus is not adequately articulated. Yet consensus building is paramount if the affected child and the family must realize high quality care.

The ways of determining the child’s capacity to make sound decisions is not clearly spelt out in the above literature. It is too presumptuous to assume every child is capable of contributing to decision-making process. It is important to note the fact that children go through different stages of development. It is therefore helpful to understand the extent to which they can participate in making critical decisions given their varied cognitive, emotional and physical capacities.

This study therefore attempted to make a contribution toward the filling up of the gaps identified above.

## **CHAPTER THREE**

### **3 STUDY METHODOLOGY**

#### **3.1 Introduction:**

This chapter describes the methods that were used in the study. It includes the research design, study area, the study population, data collection methods, data analysis, quality control measure used and ethical considerations related to the study. It explains the relevancy and appropriateness of these methods in the study. Challenges related to the methods are also explained in this chapter.

#### **3.2 Study Design**

Exploratory study design was used since the concept of children's palliative care is relatively new in Hospice Africa Uganda. This design enabled respondents to describe, interpret the nature of the problems, share their experiences, and perspectives regarding decision-making approaches children's palliative care. The exploratory study design also made it possible for the researcher to gain insight and establish the meanings behind the prevailing practice and approaches to decision-making in children's palliative care. The exploration of the views from respondents was done using informative questions, in-depth discussions centered on the research topic and the major research questions.

#### **3.3 Area of study**

The study was conducted in the three Hospice Africa Uganda sites of HAU Makindye, Mobile Hospice Mbarara and Little Hospice Hoima. HAU provides direct palliative care in the three districts of Kampala, Hoima and Mbarara as well as giving technical support to other Districts across Uganda. HAU has an extensive education/training and advocacy programme for palliative care, as well as serving as a model facilitating palliative care in other African countries. HAU clinical services, education and advocacy run concurrently. Clinical services directly inform not only the education and training components but also the policy and advocacy activities in terms of evidence based palliative care practice.

HAU was considered as ideal study area because of its vast experience in provision of palliative care in Uganda and supporting palliative care initiatives in other African countries.

### 3.4 Study Population

The study involved health professionals, family carers, children with palliative care needs and key informants such as children's palliative care specialists, volunteers, teachers, social workers, clinical psychologist). The table below presents a summary of the study population

<b>Socio-Demographic</b>	<b>STUDY RESPONDENTS (HAU)</b>		
<b>Characteristics of the study population</b>	<b>Mbarara</b>	<b>Hoima</b>	<b>Kampala</b>
<b>Profession of respondents</b>			
Doctors	1	0	1
Nurses	4	2	10
Clinical officers	1	0	0
Key Informants	2	1	3
Family carers	5	5	5
<b>Gender of respondents</b>			
Male	2	1	3
Female	5	2	25
<b>Children on programme</b>	<b>60</b>	<b>63</b>	<b>110</b>

Health professionals and family carers who have been involved in caring for children for a minimum of 3 months were considered eligible respondents. Three months duration was found adequate for palliative care practitioners to establish productive professional relationship with the affected children and also to gain better insight into the best approaches for decision-making for the children in need of palliative care services. Attempt was made to interview both male and female carers. However during this study it was discovered that the daily care is mostly provided by female, while the men in most cases are engaged in other family activities.



The key informants (palliative care specialists including social workers, clinical psychologists, teachers, child counselors) were selected on the basis of their experience and expertise in palliative care for children.

Family carers who provide unpaid, informal care to the children affected by life threatening illness and health professionals who have been providing palliative care for the targeted patients for a minimum of 3 months were involved in the study. This helped to ensure that the views they were sharing is based on experience not just theories.

### **3.5 Sample Size and Sampling procedure:**

Six-6 key informants were involved in this study. The Key Informants were purposively selected. Palliative care practitioners with expertise and with more than two year experience in providing palliative care for children qualified to be key informants. The Key Informants were derived from the existing multi disciplinary teams within the 3 Hospice sites in Uganda. Both health and non health professionals constituted the Key Informants and they were purposively selected.

Nineteen -19 health professionals out of existing 31 health professionals and 15 family carers practicing palliative care in 3 hospice sites (Makindye, Hoima, Mbarara). The respondents were sampled randomly from the 3 hospice sites (Kampala, Hoima and Mbarara).

One focus group discussion was held with children on programme in Kampala. Children in the age range of 6-17 years were identified by the Palliative care teacher. A total of 8 children ( 4 boys and 4 girls) participated in the FGD that lasted for 1 hour and 35 minutes.

### **3.6 Data Collection methods**

The following qualitative data collection methods were used; In-depth and key informants-interviews, focus group discussions, observations. These methods were most appropriate for the exploratory nature of the study. The methods were triangulated and this helped to improve validity of information gathered.

### **In-depth- Interviews:**

An Interview Guide was used and the guide centered around issues in the research questions. Depending on the flow of the discussion, the researcher had the liberty to ask more probing questions and alternate the order of the questions for coherence and consistency in during the interview sessions. In depth interview was held with Key-Informants (Experts in children's Palliative Care service provision), health professionals and non health professionals. A tape recorder was used so as to capture the details of the interviews. Respondents were given the chance to use the language of their preference and translation was done with the help of a research assistant, especially in Mbarara. Initially, a Semi-structured Questionnaire instrument was proposed for family carers and health professional, but this idea was dropped after the pre-test of the tool. The health professionals preferred having in-depth discussions in order to explain their views and perspectives regarding the subject matter. Also, since the number of health professionals across the 3 sites is less than 40, statistically it would not be possible to analyse the data with the SPSS software and the findings would not be representative enough.

### **Focus group discussions**

A Focus Group Discussion was held with children in Makindye Kampala only. The researcher intended to have a total of 9 FGDs (3 FGDs at each of the 3 HAU sites). This method was possible only in Kampala because most of the children attending day care services are relatively in better health conditions compared to their counterparts seen within Mulago and Mbarara hospitals. It was not possible for the children in Mbarara Hospital to sit for more than 15 minutes for the FGD. The children seen by HAU team in hospital set ups are usually critically ill and therefore it is not very realistic and fair to subject them to long discussions. Likewise, the carers in most cases are in a state of distress. The best the researcher could do was to hold short interviews with some of the carers, particularly those whose children's health conditions were fairly fine. It was not possible for the health professionals to spare time for FGDs. HAU service is based on the principle of "*patients and their families first!*" Therefore any activity that is not in line with this principle is not acceptable. The option of in-depth interview was preferred since it did not involve the entire team.

## **Observation**

The day to day practice of multi disciplinary team (Health workers, social workers, teachers) were observed in the course of this study. A field journal was kept throughout the study to detail observations, (reflect thoughts, feelings, ideas, hypothesis). Observation helped to maximise the researcher's ability to grasp motives, beliefs, unconscious customs and behaviour of the participants within their environment.

### **3.7 Data analysis**

The initial stage of data processing involved editing of responses from study participants. This was done daily to check completeness, accuracy and elimination of errors. Recorded interviews were transcribed verbatim and serious grammatical errors were corrected, the researcher ensured the meanings and views expressed by respondents were not distorted. Data was collected in line with the research themes. From the main themes, sub themes were generated through the process of content analysis.

Since this was an exploratory study, the researcher ensured a smaller sample size was considered for ease of data analysis. The main themes and sub themes were coded in a matrix representing views from key respondents from the 3 hospice sites. To ensure anonymity and confidentiality, all transcripts were typed using a pseudo name for each participant. Relevant quotes have been highlighted and used appropriately in line with the research themes and sub-themes.

### **3.8 Quality Control**

Data collection tools were pre-tested on health and non health professionals prior to the data collection. Through this, errors in questions were identified and corrected. Questions that were unclear were revised and irrelevant questions were discarded. Through the pretest the researcher was able to realize the need to tailor the questions to the "lived experiences" and practices in decision-making in children's palliative care. In this way theoretical discussions and views were minimized. Instead analysis was done with due consideration for existing theories and secondary literature reviewed. Experienced research assistants who were fluent in both English and

appropriate local languages were used for this study. Data collected were edited on a daily basis, gaps and inconsistencies were corrected. The researcher utilized a field diary to note any other information that could enrich the research work.

The research proposal was also presented to Hospice Africa Uganda and the Graduate School Research committee for review and approval. Feedback from the committee was incorporated in the design of the study.

### **3.9 Ethical Considerations**

An introductory letter was obtained from Makerere University (see copy in appendix I). The letter was used as a proof of objective intention of the study. Verbal consent was obtained from individual study respondents after explaining the objectives of the study. Participation in the study was not mandatory. Fortunately, none of the targeted respondents refused to participate in the study. Views expressed by respondents will be kept confidential; no personal details of the respondents were recorded. Recorded interviews are kept by the researcher. Participants were interviewed at places convenient for them and where they felt free to express their opinions.

## **CHAPTER FOUR**

### **4 FINDINGS, INTERPRETATIONS AND DISCUSSIONS**

#### **4.1 Introduction:**

This chapter focuses on the major findings in line with the following study themes; Meanings and experiences with decision-making, participants in decision-making, ethical principles used in decision-making, factors that influence decision-making and challenges in decision-making in children's palliative care. The findings are presented, interpreted and discussed in view of the research problem, general objective of the study, research questions and literature review presented in chapter one and two, respectively. This is further validated by verbatim responses and case stories from respondents.

#### **4.2 Socio-demographic characteristics of the respondents:**

The key study respondents were health professionals, family carers, children and allied professionals. A small number of children in HAU Makindye were able to participate in the focus group discussion. This was possible because HAU Kampala organises day care services every Tuesdays at its premises in Makindye, and children whose health conditions are fairly fine were able to participate. The day care activities in LHH and MHM are organised once in a month and this is usually within the hospital set up. It was observed that the children who attend the day care within the hospital set up are in most cases critically ill. As a result the planned FGD was not convenient for the children mainly due to the fact that their health conditions could not allow the researcher have elaborate interview with them. Instead the researcher opted for individual interviews with some of the children.

Most of the study respondents were adults. This partly explains the little role children in this study setting played in decision-making. Even when the researcher attempted to interview the children, very few of them had the confidence to express their views. Discussions with adult respondents across the three sites confirm the fact that very few children participate in decision-making. The few who are involved are simply passive participants, NOT by choice but mainly due to socio-cultural orientation and the painful nature of the illnesses.

Females constituted the greatest percentage of the study respondents (81%). This is partly due to the traditional care responsibility that rested with female and is still the case in most societies in Uganda. Palliative care is still perceived as a female profession. From this study, it was discovered that the male play active role in looking for and allocating resources needed for care.

Majority of the respondents were female nurses. In Uganda there are generally few doctors and clinical officers. The existing few do not have enough time for holistic care since they have high load of patients that require their attention. The study was informed that palliative care is predominantly a responsibility of the nurses, the higher level health professionals stop at the technical diagnosis and designing the patient management plan. The implementation of the treatment management plan, psychosocial, spiritual and emotional care is left to the nurses, family carers, volunteers and allied professionals since these require adequate time.

The family carers interviewed were either house wives or not employed at all. Perhaps this explains the fact that they could afford to be available to support the patients while the male family carers are busy looking for resources and attending to other family obligations.

#### **4.3 Meanings and experiences with decision-making in children's palliative care**

In this study it was important to seek for an operational definition of palliative care among practitioners at Hospice Africa Uganda. It was also inevitable to draw a clear distinction between general palliative care and children's palliative care. Respondents expressed the unique features of children's palliative care as compared to adult's palliative care. It was also important to get the meaning of decision-making from the palliative care practitioners points of view. The lived experience with decision was considered helpful in providing accurate insight into what it means to make decision in children's palliative care. The findings in relation to the sub themes mentioned above are hereby presented, interpreted and discussed.

#### **4.4 The meaning of palliative care in the context of Hospice Africa Uganda:**

The definition of palliative care by the World Health Organization (2002) and of palliative medicine when the medical specialty was accepted in the United Kingdom (1987) is widely quoted in Hospice Africa Uganda. Within Hospice Africa Uganda sites, the following conditions are required for a disease to be considered appropriate for palliative care: (1) progressive, incurable, advanced disease, (2) lack of a reasonable possibility of response to active specific treatment, (3) multiple problems or symptoms that tend to be intense, multifactorial, and changeable, (4) high emotional impact in the patient, family, and team that is related, explicitly or not, to the proximity of death.

The definition also describes comfort as the main objective. The basis of the therapeutic approach is integral care, patient/family as a unit of care, promotion of autonomy and dignity, active therapeutic approach, and care of the therapeutic milieu. The basic therapeutic tools are symptom control, emotional support, honest communication and a multidisciplinary team.

There is high emphasis on *life threatening illnesses* instead of *terminal illnesses*. Patients on palliative care are not necessarily considered terminal. The use of the word terminal denotes a sort of ‘death’ sentence. From experience, it has been noted that even patients with what would otherwise be regarded as terminal may steadily regain their health and live longer like any other patients with other ill health conditions for example persons with HIV/AIDS tend to live longer, with good palliative care and support care interventions.

Much as HAU team would wish to serve in line with the holistic approach-with focus on physical, psychosocial, social and spiritual care, more emphasis is given to the controlling the physical concerns/care needs of patients and their families. The teams capacity to respond effectively to the psychosocial, social and spiritual concerns need to be boosted. At the time of this study, only one site (HAU-makindye) had a professional social worker. The rest of the palliative care team are able to offer basic psychosocial and spiritual support.

Study respondents emphasised the need to start palliative care from the time the disease is diagnosed up to bereavement. Similarly, Nabukera et al., (2007:123-131) believe palliative care

should begin well before the child is extremely ill or dying. It should be integrated with other treatments early in the course of the illness. It is appropriate for both children who are born with illness and those who develop illness at later stages of childhood or adolescence.

From experience, most of the patients seen by HAU palliative care team come when other treatment options such as curative and other non medical interventions have failed. Patients report for hospice care when their resource envelope is exhausted and during this stage, carers manifest a lot of distress and some of them are extremely devastated. The delay to start palliative care is attributed to the fact that curative experts take too long to recognise or admit the fact that a particular patient requires palliative intervention. This means decision-making is delayed by both family carers and the health professionals. The delay on the part of family carers is attributed to factors such as traditional beliefs about illnesses, poor health seeking behaviours, control of decision-making power by men, among others. Lack of palliative care knowledge mainly explains the delay on the part of health professionals.

“Some of our health professionals, especially those inclined to curative practice find it difficult to admit the fact that their interventions are not helpful anymore. It is common to see them putting Intravenous fluid lines on patients and oxygen on patients who are showing all signs of end of life.”. A palliative care nurse in Mbarara.

Children’s palliative care practitioners at HAU assert that palliative care is not meant to prolong or shorten life. It is to give comfort to patients and families who are faced with life threatening or limiting illness. Similarly, Stephenson (2000) argues that the goal of children’s palliative care should be to *"add life to the child's years, not simply years to the child's life."*

Depending on the severity and the duration of the distress, different patients have varied wishes. Patient with prolonged severe pain may not see much meaning in staying alive. Family carers on the other hand prefer having their loved ones live longer despite the stress related to providing care to the patient. On top of giving comfort to the ‘dying person’ a carer’s wish is to see “days” added to the life of the patient, not just life to the remaining days!



Much as the priority is not to add days to life, study respondents acknowledge the fact that palliative care actually improves the quality of life of the patient to the extent that they are able to live longer than similar patients who have not had access to palliative care. Indeed it was observed that over time, the health conditions of some of the children on hospice programme have tremendously improved, especially the HIV and AIDS affected children. In cancer patients very little may be done to prolong life. Prolonging life in cancer patient implies prolonging suffering. The longer a patient lives with the debilitating conditions, the longer the chances of experiencing pain.

#### **4.5 Meaning and uniqueness of children's palliative care**

Palliative care practitioners recognise the fact that children are not just little adults! Respondents across the existing HAU sites reported that Children's palliative care is a special branch of palliative medicine. Similar to the general concept of Adult palliative care, children palliative care was perceived by study respondents as "the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease." This understanding of Children's palliative care is also shared by the Joint United Nations Programme on HIV/AIDS as achieving the best quality of life for patients and their families who are suffering from life-threatening and ultimately incurable illnesses (UNAIDS, 2009). The United Nations Programme further specifies that palliative care should be provided for all people living with HIV/AIDS, not solely for people approaching death.

Children's palliative care is regarded as special because children present a number of challenges in assessment, management and communication.

“Management of children is different because they respond to situations differently compared to adults. In terms of drugs we have to be cautious with their dosing schedules, they have different needs from adults. They require special approaches in a holistic way”.  
A Palliative care Nurse in Makindye –Kampala.

Similarly, Hynson et al, (2003) reported that Children need very different types of approach, for various periods of time and entail an emotional involvement that amplify the energy demands and call for a multidisciplinary action of a highly complex nature. They recognize that children are in continuous physical, emotional and cognitive evolution, and this affects every aspects of their care, from the dosage of medication to the choice of methods for communication and support;

Feedback from study respondents revealed that children depend on their parents for decision-making purposes. This was further confirmed by the focus group discussions with children on programme in Kampala. According to some respondents, children bellow the age of 7 years need to be guided by their parents to make decisions. Depending on the age of the child and the influence of the socio cultural environment, a child may not effectively participate in palliative care decision-making. Such children greatly rely on decisions made by their family carers and health care team.

“ Children on programme face a number of traditional norms that inhibits their participation in decision-making. Young children depend on their guardians to make decision. Most parents and guardians harbour policy of protectionism. They are hesitant to share the diagnosis and prognosis with the affected child. They are usually afraid of breaking bad news to children. Some parents under look children and assume they lack potentials to make decisions”. A Key Informant in Little Hospice Hoima.

Depending on how these children are cared for by the palliative care practitioners, capacity of the children to effectively contribute to decision-making processes could be enhanced. There is need to design children's palliative care needs assessment to the aspirations, beliefs and values of the affected child. Through interactions with some of the children on programme at the time of this study, it was noted that dealing with children requires adequate time and patience. It takes considerably long for an affected child to gain confidence and trust with a care provider.

According to the children's palliative care nurses at Hospice Africa Uganda programme area, the longer a child stays on hospice programme, the more informed they become about their health conditions. This makes them capable of contributing constructively to decision-making processes.

It was noted that children who attend day care programme regularly become more confident and assertive to express their feelings and concerns. The day care provides a setting for them to express their concerns, wishes and aspirations through songs, story telling, drawings and open sharing with the palliative care nurses, teachers and volunteers. It is important to note that a child of 5 years may reason like a 10 years child, so it is important to involve them.

Most health professionals and family carers lack adequate skills to communicate with children. As a result, most of the time decisions are made by parents. Communication approaches used for children is significantly different from adults. Children may not express themselves the same way as adults. It takes time for a child to open up to a palliative carer. Children see things different from the way adults see things.

“For children it is not that easy, it may be difficult to know what is happening to them. It might not be easy to explain to them what is happening. It is very difficult to explain to them because of their varied levels of understanding. You may not tell how the child will react to the bad news.” A palliative care nurse in Mobile Hospice Mbarara

Palliative care practitioners also acknowledge the fact that children are observant and intelligent regardless of the age. According to the palliative care specialists, children above 7 years have a clue of what is happening because they hear what is happening and some of them have seen somebody who has had such a problem.

In summary, it is very important to note that children make very special patients: this is already true when it comes to deciding a course of treatment, but even more so in palliative care setting. The spectrum of conditions requiring children’s palliative care is broad and heterogeneous. The duration and complexity of the patient care required are equally varied.

#### 4.6 Meanings of decision-making in children palliative care

Decision-making in children's palliative care is perceived differently by respondents depending on their professional orientation, experience in children's Palliative care, socio-cultural orientation, among others. To most of the study respondents, children's palliative care decision-making means *involving the child* in taking action regarding their welfare. Prior to decision-making there is need to examine the age and socio economic background of the affected child. Respondents believe decision-making should be based on thorough discussions and explanation of the benefits and the disadvantages of the proposed actions. An interactive discussion with the affected child was recommended by palliative care practitioners at Hospice Africa Uganda.

Respondents suggest the need to find out how much the child already knows, what the child expects from the care provider, their fears and concerns. This dialogue helps to create a sense of responsibility and ownership of the outcome of a given decision. Most parents would wish to protect their children from harmful information. Therefore disclosure of information to a child must be handled carefully. The prevailing culture largely ignores open discussion and participation of children in palliative care discussions. Health practitioners in particular recognise the relevancy of involving the child in decision-making process. When children are not involved in decision-making process they may refuse drugs and the symptoms may worsen and the child ends up dying.

Focus group discussions with children on programme at Hospice Africa Uganda revealed that, Involvement of children is not just a formality but is also a right! Children involved in this study feel they know themselves better and should be given the chance to contribute to the decision-making process. According to the children who participated in this study, decision-making means *being able to say what you want without being coerced*. Just like adults, children also feel that with adequate information from care providers especially health professionals, they could contribute to good decision-making.

Much as children have the rights to participate in decision-making, in practice this may not be possible depending on the circumstances. Experiences such as narrated above are not desirable by children, as one child respondent (10 years) expressed it;

“Some children do not exercise their rights to decision-making, even when they are aware of it. Some parents and health workers are too harsh. Children’s rights remain in the constitution. Even when a child is old enough some parents assume they know them better. It feels good for me to participate in decision-making, it reduces worries.” ( A 16 year old girl child on Hospice programme)

To most family carers, decision-making means *giving a chance to the child to know what is happening* because it is their right. Many times they want to know what is happening but adults are frightened and do not want to tell them. So they keep them away from knowing. It is vital to give all the necessary information and allow the family members and the children the chance to make decisions. The family carers reiterate the need to consider the views, wishes and values of the affected child.

It is still a great ethical dilemma to know whose views to consider. The usual practice is for health professionals to rely on the input of the family carers. Findings reveal high socio-cultural influence on decision-making. The person whose views matter in most cases is not the person who is with the patient every moment. The tendency is to follow the views expressed by the father of the affected child or the person perceived as the *‘Bread Winner’*. Observations and feedback for palliative care practitioners indicate over 80 percent of the family carers are females and yet few of them are empowered to make critical palliative care decisions with or without consulting the male family members or the head of the family. This cultural orientation greatly contributes to delay in decision-making process.

Apart from the child, in palliative care, the views of the family members are also very important. Palliative care specialists rely on family members in providing primary care for the affected child. They are in daily interaction with the child. They may understand the child better than palliative care practitioners. This therefore means their views should be respected and palliative care for the child must fit within the family expectations and should be culturally appropriate.

#### **4.7 Types of decisions made in children's palliative care**

Several decisions are made in the course of children's palliative care. Such decisions may include; When to give treatment, when to discharge the child or not. Decisions regarding treatment options are mainly made by health professionals. Study participants suggest that in every decision, the holistic analysis should be done. The physical, psychological, social and spiritual contextual issues should be critically analysed.

Study respondents emphasise the need to discern whether the wishes and aspirations of the affected child are rational or not. A child may refuse the treatment. Health professionals should be in position to help the child understand the importance of the treatment. A child may not want to stay with some family members. Depending on their role in the life of the child, it is helpful to explain to this child why he or she should stay with the mentioned person. It depends on the child's level of understanding. A carer should use his or her judgement at times to make decision on behalf of the child.

“Last year we had a child who was terminally ill. The health professional felt the child could not stay longer in the hospital but they feared to tell the carers. Hospice was called to intervene. I went over and called for the mother and the child. After inquiring more about how much he knew about his conditions and explaining to him what is happening, he was ready to receive the news and he accepted the bad news. I asked him about his wish and then he told me he needed a radio to keep listening to while at home. We provided this to him. After 3 months, he passed away. But we were happy that we listened to his wishes and feelings”. A palliative care nurse in Mbarara.

Study participants reported the fact that the voices of doctors tend to override the rest of the stakeholders when it comes to treatment or medical decisions. Treatment decisions are very critical, according to the health professionals. Some of the drugs require high level of adherence and some drugs may be toxic in nature, thus requiring good administration. This requires the commitment of the health worker, affected child and the family carer. It is very important to get the support and commitment of all the stakeholders in such treatment decisions. Collective and participatory decision-making is recommended.

Palliative care team very much attempt to respect the wishes of the children. Sometimes decisions are limited by resources; for example, in order to give chemotherapy, certain investigations have to be done and where there are no funds, it becomes difficult to make decisions. This does not mean that children and their family members lack the capacity to contribute to decision-making process.

In view of the above an 8 year old child on programme at Hospice Makindye remarked, thus;

“Much as the doctor may know my health conditions better, it does not mean I have nothing to contribute. Sometimes if issues are explained to me, with the help of my counsellor I could also contribute to the decision-making. Sometimes doctors give us drugs without consulting us yet these drugs have a lot of effect on us. Some of us may not be able to afford good nutrition to control the effect of the drugs.”

From the above sentiment it is important to realise the fact that regardless of the type of decisions, children could be helped to share their concerns and feelings regarding proposed treatment options. It is important to realise that decisions regarding the life of a child affect them in different ways and all key people should be consulted before making a final decision. If for some reasons the primary decision makers do not feel comfortable to consult a child then they could utilise the services of professional counsellors, as per the preference of the affected child.

A critical analysis of surrounding circumstances is important in order to share information. For example if the child is about to sit for his/her exams and yet you have discovered that the child has terminal illnesses, then you may need to delay the process of disclosure. Decisions regarding referral need to be made collaboratively since this may involve costs and social adjustments at home. Decisions to care for a child at home or not, whether to put the child on IV fluid or not, may call for dialogue. From the palliative care point of view, it may not be helpful to put the child on IV fluid at certain stage of care. You may need to discuss this with stakeholders in professional and non confrontational way.

#### **4.8 Participants in decision-making in children's palliative care**

Family centred care is highly valued by palliative care practitioners at Hospice Africa Uganda. Family Carers of the affected child are very important because on a daily basis they relate with the affected child and understand him/her better. This view is further upheld by Nabukeera et al (2007), Hynson et al (2003), who view family involvement as a key resource in decision-making. Jonsen et al (2002) also perceives family centred care as a core value of children's palliative care. Study participants reported that family members are actively involved in providing care and have a great deal of responsibility for caring for the child, having to make often difficult decisions in the child's best interest, and paying the social and economic price of incurable disease.

Similarly, European Association of Palliative Care (2005) strongly emphasize the *role of family in children's palliative care*. It is observed that all children are members of a close-knit unit consisting of their family, which has a very special role when young patients develop incurable, chronic disease. Parents legally represent their offspring in all clinical, therapeutic, ethical and social decisions. The family has a pivotal role in communications with healthcare providers and institutions, and if the child remains at home, then patient care and treatment is delegated to the family. Other members of the expanded family also play an important part in creating a sharing and affective support network with a cascade effect on the sick children's and their parents' quality of life (EAPC, 2005).

Given the value of involving affected child's family members, it is very important to ensure that the involvement is well coordinated in order to ensure meaningful results for the affected child. At times co-ordination is challenging because some of the carers do not have time to listen to the patient. Consensus in decision-making has not always been possible due to lack of shared understanding of the patient management plan. It is sometimes difficult for joint care team to arrive at a shared understanding of palliative care needs of the patient and the family. Literature offered by Hynson et al (2003) emphasize the importance of contextualizing and assessing the needs of the team taking care of these patients and their families, and of the institutions that have to meet these new needs and find new ways to provide patient care.



Multi disciplinary team involvement is commonly practiced by palliative care service providers at the three HAU sites. In Mbarara and Kampala, the children's palliative care team use joint care approach, involving the curative team (host hospital) alongside the palliative care team. The joint care team complement each other in a coordinated way. Similar to findings by Webb P (2005), multi disciplinary team was highly recommended by study participants for decision-making. Each team member brings on board a unique expertise and role. Within Hospice Africa Uganda programme sites, the team usually includes a social worker, a counsellor, a physician, a clinical Psychologist, and family carers, among others.

In all the 3 HAU sites study participants reported the challenge of working with multiple decision makers. Not every member of the team might have a shared understanding of the patient management plan. Likewise, Worthington R (2003) reported that not everyone believes in benefits of team decision-making. He argues that some health workers and family carers are more independent minded. The experiences of palliative care specialists in this regard have not always been the best, as expressed by a palliative care nurse during the study:

“There was a time we needed to take a child for radio therapy, the father of the child refused for fear that the radioactive rays would affect the child. Despite our explanation, he refused. Because of this condition, we could not proceed with the suggestion for radio therapy. Eventually the child died”.

Family carers involved in this study expressed high trust in health workers to make treatment decisions. According to Jonsen et al (2002), health workers are expected to educate and inform patients and family carers about treatment options and recommend decisions he or she believes is in the best interest of the patient. This does not leave carers totally dependent on health workers for decision-making. It was reported that, in certain circumstances carers take decisions; for example, moments like desire to care for the patients at home in order to minimise expenses. Health professionals reported that some carers do not know their role or right to participate. Sometimes they may lack the confidence to participate or make independent decisions.

During focus group discussion with children, a high level of honesty and transparency was observed. With good rapport, children freely express their feelings, wishes and aspirations. Unfortunately, sometimes parents and professional carers do not give children the chance to express themselves. In most cases children are denied the opportunity to follow what is taking place or send them to go and play away from them. Ethically, every patient who is mentally stable is supposed to consent. Children too need to be supported to make decisions.

“Winnie Babhika (not real name) is a 13yr old girl who presented in Mulago with Orbital Lymphoma after being referred from Tororo hospital. She was in severe pain and having problems with her vision and hearing. After two weeks in hospital she completely lost her sight. It was very frustrating for Winnie. She was not able to play with the other children on the ward, go to the toilet or even dress. Winnie felt very lost in her new world. One day as the team was discussing with Winnie’s mother about her condition, Winnie burst out crying uncontrollably. When she was asked what the problem was, she said why they are asking you instead of me about how I feel. This made the team realize that although Winnie was blind, she still had the capability to make decisions. Involving Winnie in her management by asking her what she desired most, made it possible to meet her needs. For example she wanted to play with the other children on the ward, so she was given toys which also helped her identify things but, she became less fearful about leaving her bed”. As told by children’s palliative care Nurse in Kampala during the study.

Although Winnie’s mother wanted her to be able to see again, Winnie just wanted to go back home and we even discussed joining a school of the blind. Winnie’s decision was respected and she returned home and the team was able to continue communicating with her. She was very grateful that she was home with her siblings and after a month she died a peaceful death..

Much as health and non health palliative care practitioners value child’s participation, in most cases it is the parents or adults who make decisions. The common justification is that some children are too young to participate. Studies by Goldman et al., (1994, p. 107-14) recognise the fact that the ability of children to participate in decision-making varies, depending on factors such as age, level of illness. They acknowledge the fact that a child’s cognitive ability may be retarded by the illness and in some instances the experiences of ill health may empower the affected child with knowledge about his/her health conditions, thus making it possible for them to effectively contribute to decision-making process.

During focus group discussions with children, it was discovered that children of different ages and socio-economic background express themselves in different ways. Some use more of non verbal communication cues and others, especially those from affluent families may be in position to articulate their concerns. The approaches and the experience of the care giver in dealing with children highly determine how helpful a child could be in decision-making processes. Most health and non health carers are not patient enough to initiate and sustain communication with children. The socio economic bias is not only manifested among family carers but also among trained health and non health professionals.

In summary, the multi disciplinary team approach is desirable in palliative care decision-making. The team helps in creating positive synergies and each member of the team always has a special contribution to make in providing quality palliative care for the affected child. Multi disciplinary team involvement further improves the nature and quality of interaction between members of the team. Involvement of family carers provides useful information to health workers. It is reported that team involvement facilitates ethical validity of decisions made.

#### **4.9 Ways in which family carers are involved in decision-making**

Family centred care has been advocated for in most similar studies. For instance Carnevale (1996) in his study perceives a child as being part of the family unit and decisions about that child must be made within that context. Family carers are known to have better knowledge of the affected child and sometimes better than the care providers outside the family setting. Parents in particular feel good and valued about being involved. It is believed that when critical illness occurs to a child, the family is intimately affected and challenged. Much as scholars uphold the principle of family centred care, family carers rely highly on health professionals for decision-making. However, the need to involve family carers in the process of decision-making is emphasised. The ideal scenario is for palliative care practitioners not to decide on behalf of the patient and the family carers but rather to advise the patients and family, through information and providing options.

The following are the suggested ways of involving Family carers in decision-making;

Through meetings and open discussions about the condition and management plans. Carers feel good about knowing what is happening to the child. In all circumstances a parents should know what is happening.

Through this study, it was discovered that most carers depend on what health workers tell them. But when issues are explained to them they can participate. But some carers make their own decisions. Nearly half of parents of affected children report that physician communication always made them feel hopeful. Parents who reported receiving a greater number of elements of prognostic disclosure were more likely to report communication-related hope, even when the likelihood of a cure was low per element of disclosure with likelihood of a cure. Although physicians sometimes limit prognostic information to preserve hope, they found no evidence that prognostic disclosure makes parents less hopeful. Instead, disclosure of prognosis by the physician can support hope, even when the prognosis is poor.

There is need to empower and encourage carers to participate. By explaining the role of hospice and what it does, family carers get to appreciate their roles more. This helps carers make decisions whether to enrol the patient on programme or not. Findings by Clayton (2008) recommend balancing hope with honesty is an important skill for health professionals when faced with challenges of disclosure. Many patients seem to be able to maintain a sense of hope despite acknowledging the terminal nature of their illness. Patients and caregivers mostly preferred honest and accurate information, provided with empathy and understanding.

#### **4.10 Ethical principles for decision-making in children's palliative care**

In practice, ethics in children and adults can be different in very important ways. In this study, it was discovered that in comparison with adults, children may not fully understand their illnesses and treatments, and even if they can, they may not be able to communicate fully their thoughts and wishes. These factors greatly affect how decisions regarding children are made and communicated. According to palliative care practitioners, it is very important to address the question of; what needs to be decided, who decides and how do they decide? These decisions should be ethically sound. The critical ethical principles used in making decisions are depicted in the case story below;

Janet (not real name), 6 year old girl was referred to Hospice Africa Uganda by a community volunteer. The children's palliative care nurse visited her in her parents small house in a slummy Kisenyi parish-in Kampala. Janet lived with her mother who separated from the father. Janet had advanced HIV/AIDS. On arrival to her home, the CPC nurse found Janet locked in the house and was faintly crying by herself. On asking her neighbour, the Hospice staff discovered the neighbour had the key and he was able to enter the house. According to the neighbour, Janet's mother had gone to the shop and would come back soon. The Hospice staff discovered Janet's health had badly deteriorated and she could not easily express herself except crying faintly. Her nuerological system was grossly abnormal. The staff noticed her hearing was partly intact. A pack of expired ART was found besides her bed, suggesting she had been on treatment. The CPC nurse could not instantly make further treatment decisions. He felt it was in Janet's best interest that he waits until he had a chance to assess her with the mother and get detailed history. The neighbour was asked to inform Janet's mother to bring her to Hospice Africa Makindye for further care and support. Eventually, when Janet's mother came, detailed history was recorded. The team discovered that she too was HIV positive and very poor, surviving from a cleaning job. She informed the team that Janet can no longer help herself and neither can she walk. Janet's mother has no immediate family support due to stigma and discrimination. For this reason, she can only

leave Janet under the care of her neighbour while she goes out to look for means of survival.

In view of the above case story, the palliative care nurse needed to determine the critical decisions to be made. The above case story presented a number of ethical dilemmas. For instance the nurse needed to answer the question of whether to; break into the locked house? Should he report this as a case of child neglect to the local Council? Should Janet be discussed with the neighbours? Should Hospice take over the care for Janet now that the mother is not available? Should Janet be examined in the absence of her mother? Should Janet's ART be withdrawn? Is the service Hospice is providing in the best interest of Janet?

In the case of Janet, she was only 6years old and even if she had been aware and intelligent, it would have been difficult to argue that she was fully competent to decide for herself. Given that she had severe neurological disorder and could not communicate except by moaning or crying, it was concluded that she was not competent to decide for herself and other people had to look for other ways of making decisions about her care.

It was clear in the case of Janet, she was incompetent to decide. Even the neighbour met was not very much interested in Janet and so could not serve as a substitute decision maker. The palliative care nurse had to make his own decision before the mother reported to Hospice. Upon arrival, it was clear the mother had the best interest of Janet at heart. She automatically became Janet's substitute decision maker. She knew much more about Janet than Hospice Nurses. However she could not act as the sole decision maker because she lacked some facts regarding possible treatment options. She had no previous records of tests carried out and she could not recall them clearly. Hospice staff tried all they could to answer the pending questions regarding the treatment options and plans.

It is therefore clear that once the dilemmas have been clarified and the questions of who should be involved have been settled, the final step is to determine how to make decisions. A number of ethical principles were shared by study participants across the three hospice Africa Uganda. Among others;

Participation of the child is a common ethical principle highlighted by study participants. Health professionals and allied professionals acknowledge the value of involving the child in decision-making. When giving palliative care to an affected child, there is need to consider “what is in the mind as well”. Much as the child’s participation is important, Alderson & Goodey (1998), Bridson et al, (2003), caution that children’s participation depends on the level of competence or capacity, rather than age or life experiences. If the affected child is able to understand the effect of the proposed decision and its consequences then he/she is considered competent and capable of making decisions (Corner J, 1997) . Richard & Jassal (2006) also reported great variation in a child’s ability to participate in decision-making.

Similarly, Amery, (2009) discovered that at times the experience of chronic illnesses, increases a child’s knowledge about the health conditions. This further improves their ability to constructively participate in decision-making process. Through this study, it was discovered that children actively participate in decision-making and some even take the leading role in decision-making, with support of palliative care practitioners. They need adequate information in order to make decisions. Their participation however requires patience. The case story below further augment this point of view;

Tricia (Not real name) is a 10 year old-orphan. Has been hospitalized with cancer of the stomach for the last 2 years. Her guardians experienced immense distress through the last 2 years. One day a palliative care team discussed the idea of her returning home since there was no much improvement. After open discussion with her and her caretaker Aunt, HAU team transported her back home. The first two weeks at home was very exciting due to change of care environment and the fact that she could easily see and talk to her fellow children in the neighbourhood. Unfortunately, this peaceful moment was short lived. She continued experiencing extreme pain.

Considering the distress the caretakers and her maternal uncle went through while caring for her in the hospital, her uncle decided not to return her back to the hospital. He resolved to let her die from home. Tricia apparently had a strong will to live and preferred returning back to the hospital for hospice care. Given the poor power relations in that family, her carer taker aunt could not easily influence her uncle to allow her come back to the hospital.

Fortunately for Tricia, one day a Community volunteer visited her at home. On seeing the high level of pain and distress she was going through, the CVW alerted Mobile Hospice Mbarara team. Tricia was picked from home and has since then been returned to Mbarara hospital. Tricia has resolved never to go back to her uncle’s home. Her wish is to die from the hospital.

The palliative care team and her caring Aunt have accepted her wish and continue to care for Tricia from Mbarara Hospital. Since then Tricia's condition has fairly improved, she communicates freely and openly with Palliative care team. She contributes constructively to decision-making process. She is well informed about details about her medications and the treatment plan". As told by a children's palliative care Nurse in Mbarara during the study.

This study exposed the fact that in most societies in Uganda, Children do not participate or understand palliative care decisions made. Similarly, Webb (2009) reported that parents may wish to protect their children by not informing them about their ill health and the likely implications. Individual interviews with some of the children on hospice programmes further attests to this finding. Culturally children are protected. Some adults avoid giving bad information to children. They protect them from the pain.

"Culture dictates that a child should only be seen not heard. Even when a family member dies, children are not informed. Instead they are taken away. If the norm dictates that girls should not eat eggs even when they are malnourished then you may not do much. Since palliative care must be culturally appropriate. We need to protect their wishes.". As told by a palliative care nurse in Kampala during the study

Age factor is a critical determinant of a child's level of participation. Depending on the age, certain decisions may be made by the carers and this also calls for good understanding of the conditions of the child. Carers need to understand why they have to take the decisions and the benefits of taking such decisions. Contrary to this, Carnevalle, (1996) argue that regardless of the child's age, he/she is capable of contributing to decision-making process, provided they are engaged in a developmentally appropriate manner. Amery (2009) is fully in agreement with this argument. He advises palliative care practitioners to endeavour to understand and apply child friendly communication techniques and establish rapport with children for better results. It is important to generate adequate information to determine decisions. Carer's role is to take care of the child and this increases knowledge and understanding of the child.

"A smile from a child is a key message, when a child is withdrawn that means a lot. We need to be observant. The challenge is that children may not easily initiate decisions". A Medical doctor at HAU makindye.



Much as children's level of understanding may not be the same as that of adults, they should not be taken for granted; they normally observe what is around them. The children admitted in cancer wards in hospitals observe fellow patients, some of whom die in their presence and they can easily relate this to their own conditions. Children may ask challenging questions. It is always important to seek their understanding about the issue before giving them your views.

In view of the above argument, Baker (2007) emphasise the individualized care planning and coordination as a practical approach to facilitate ethical and effective decision-making in children's palliative care. This minimises contentious family-staff interactions that can lead to mistrust and help guide treatment decision-making. It enhances communication among patients, families, and clinicians by revealing patient and family values and medical and quality-of-life priorities before reaching or even during critical decision points in the transplantation process.

Study participants reported that children too are expected to exercise autonomy in decision-making. Likewise Harrison et al, (1997) advocates for respect for a patient autonomy and self-determination. According to their report, physicians must obtain informed consent from a parent or substitute carer before a child can undergo medical interventions, other than in the case of emergencies. As a component of informed consent, the health worker must consider and discuss with the family the risks and benefits involved with each decision.

The principle of autonomy is quite challenging to apply for children who are regarded as minors. From 6 years and above, children may be in position to make autonomous decisions under guidance of palliative care team and family carers. Contrary to this, Alderson & Goodey (1998) argue that autonomy depends on level of competence or capacity rather than age. For children, autonomy in decision-making can best be facilitated through accurate and clear information given about prognosis and diagnosis. Roger (2005) agrees that Health workers have the obligation to guide the affected child to understand the health conditions and participate in making decisions. Assessment of a child's level of knowledge about the situation should be done. Relevant information should be provided according to their level of understanding and the

right communication strategies. Children are rational and understand, provided they are helped by adults to understand what is going on.

Depending on the socio-cultural context, in some societies autonomy for children may not be easily appreciated. In a culturally suppressive environment palliative care practitioners need to be very sensitive with their approaches. Steinhauser et al (2000) also acknowledge the key role culture has on the practice of child's autonomy. Depending on the setting, culture may either promote or inhibit a child's freedom to exercise autonomy in decision-making. Application of the principle of autonomy is more challenging with children than adults. The fact that you are dealing with multiple stakeholders further complicates the application of these principles. Autonomy is more applicable to the family carers/parents since most of the decisions are made by the parents on behalf of the children.

“Kamara (Not real name) is a 9 year old child who has been under children's palliative care programme since 2008. He has been on sixth line chemotherapy. Even with the sixth line chemo he has shown no improvement. Palliative care team preferred to care for him at home near Kitovu Mobile Hospice in Masaka district since the available treatment options have failed. However his mother is not in agreement. Apparently Kamara was her only child. She strongly believes alternative care options can be found within Mbarara hospital. After long negotiations she agreed to take the child home in Masaka. On reaching home she declined to take Kamara for care in the nearby Hospice (Kitovu Mobile Hospice). Kamara never had the chance to express his own wishes and preferences. Her mum always wanted things done her way. After 1 month of return home, little Kamara died”. As told by a children's palliative care Nurse in Mbarara.

It is common for the interests of the family carers to override that of the affected child and this is a big ethical dilemma, especially in situations where there is unequal power balance in the family and where the cost of legal services are not very affordable.

“We once had a parent who was a Jehovah's Witness by faith, he had a child who was anaemic and needed blood transfusion. Because of his strong believe in his faith, he refused to allow blood transfusion and as a result the child died”. A children palliative care nurse at HAU Makindye.

Palliative care practitioners reported that they have the obligation to serve in the best interest of the patient and their families rather than their own. According to study participants, the beneficence principle is practical when adequate information is given to the client. They consider it helpful to discuss relevant options, their pros and cons, to guide the process of decision-making. In agreement with Jonsen et al (2002), Palliative care practitioners reported that in certain circumstances they used their judgements to make objective decisions.

Professional and personal values enter heavily into what one member of the health care team considers the "right" decision, and these values may interfere with the decision-making process of the team. As team members begin to realize how their ethical values affect the decision, they may be better able to resolve the conflict within the team. An understanding of each member's ethics and values also can serve to enhance decision-making. According to Wocial (1996) ethical decision-making is a process that combines justice and caring in moral reflection to select sound choices. Nurses and physicians often have different perspectives on how to resolve ethical dilemmas. Satisfactory resolution depends on overcoming conflict and achieving collaboration between members of the health care team. Conflict can occur on a number of different levels. For example, it can be between nurses, nurses and physicians or the entire health care team and the patient.

From the interview with Children on Hospice Africa Uganda programme, it was observed that many children can make morally mature decisions before they are legally entitled to do so. Therefore, older children and adolescents should be included in the decision-making process (patient assent), depending on their neurologic status, development, and level of maturity; however, legally, they require a surrogate decision-maker to act on their behalf (ie, parental permission). What parents actually do, therefore, is to give permission for a treatment or surgery on their child; only a competent, fully autonomous individual is capable of giving consent, and then only for himself.

“In Uganda, Children are persons in the social sense and they have rights, but they are not judged legally competent to make decisions about their medical treatments until they reach the age of majority, ie, 18 years. Therefore, children cannot give consent for themselves, but they can assent to procedures, either indirectly (by their acquiescence) or

directly when they are involved in the discussion”. A Key Informant-Social Worker in Kampala

Similar to the practice in the USA, according to Pellegrino et al, (1998) some minors are considered emancipated and, therefore, able to make legally autonomous decisions in most states. This category often includes: those in the military, those legally married, those economically independent; or those who are parents of a child. Some state's courts have even recognized a status of mature minor, an adolescent who does not fall into the above legal categories but possesses sufficient maturity and intellect to be allowed to make autonomous decisions over parental objections. This last category offers no predefined legal protection for the minor or the physician who would allow him or her full decision-making authority.

According to Committee on Bioethics, American Academy of Pediatrics (1995), a child's surrogate, usually a parent, should be the person judged to be the most competent to determine what actions are in the best interest of the child. This presumption holds when the parent or surrogate appears to be acting in the child's best interest and otherwise can be challenged. Whether or not the child is able to participate in decision-making, treatment decisions should consider potential benefits to the child; potential harmful consequences (eg, physical suffering, psychological or spiritual distress, fatality); and the moral, spiritual, and cultural values of the child's family.

In summary, this study finding indicate a high level of awareness of the key ethical principles among palliative care practitioners at HAU. Much as palliative care practitioners are aware of the ethical principles, application of the principles depend on factors such as the level awareness about the rights of patients and families, level of physical, cognitive and emotional maturity of the affected child, severity of the illnesses especially pain. When a patient is in extreme pain, sometimes their participation or consent on critical decisions may be hard to enforce.

Traditionally, health professionals are expected to make rational and objective decisions that are geared towards improving the welfare of the patient and their families. It takes wisdom from a health worker to realise the need to involve patients and their family carers in the process of decision-making, especially when they have adequate capacity to positively contribute to the decision-making process.

#### **4.11 The meaning of Best interest in decision-making in children PC**

Study participants gave varied definitions of the concept of “best interest” in decision-making. To some respondents ‘Best interest’ meant;

The child understands what is happening to him or her and whatever management is given to the child should be explained. This is in agreement with views of Bridstol et al (2003), who emphasise the need for health workers to explain every step taken in management of the affected child. The effects and implications should also be explained. Roger (2005) reiterates that the affected child also needs the assurance that everything is being done to make things better for him or her.

Health workers also emphasised the need to consider what the child wants not what relatives or adults want. Similarly, Campbell et al (2001) advocated for combination clinicians knowledge, experience and the understanding of values, beliefs and expectations of the affected child and their families. This process calls for open discussion with the affected child and this certainly requires disclosure, which some parents may be opposed to. As observed in the previous discussion some parents would wish to shield their children from knowing the truth about the health condition.

According to health workers, for a decision to be rated as in the best interest of the child, the benefit should outweigh the risks. They recommend that decision must be critically analysed in view of the risks and the expected benefits. This process should involve all the key stakeholders. According to Jonsen et al (2002) are expected to use their professional judgement in assessing the benefits of the decision. Decision-making goes hand in hand with how much knowledge is available. To some extent the financial and economic position of the carers also determines whether a decision will be considered or not. Some decisions are limited by the fact that there are no resources to back up the action.

In defining the best interests, decision makers endeavor to do what is best for the affected child, no matter how marginal the benefit or what the interests of others are. The definitions are largely oriented towards the child – it recommends only the child’s interests are considered. Other

people's interests are ignored, particularly those of parents and siblings, or are only considered in so far as they impact on the interests of the child. Reece (1996) advocates for a framework which recognises that the child is merely one participant in a process in which the interest of all the participants count. Herring (1999) on the other hand proposed the need to adopt a "relationship-based welfare approach", in which the child's welfare is understood in the context of a parent-child relationship, "preserving the rights of each, but with the child's welfare at the forefront of the family's concern".

Decision in the best interest in the context of African –Ugandan culture is largely subjective. In a few instances the child's interest and wishes are taken seriously. The views of adults, health professionals, family members-especially the 'bread winner' is largely upheld regardless of the wishes of the affected child. Depending on the type of decision, sometimes health professionals assume absolute role in making decisions on behalf of the affected child and family members, especially medical/treatment decisions.

In summary, definition of the concept of "Best Interest" involves consideration of many factors. Multi disciplinary team involvement to make accurate judgement is highly recommended. Through regular meetings and case conferences palliative care practitioners at HAU have been able to help stakeholders examine the implications of any decisions made for a patient and the family. Every decision made should be based on well thought plans and should be ethically approved. The interpretation of the concept of best interest in decision-making varied from one respondent to the other.

#### **4.12 Factors that influence decision-making in children's palliative care**

In most families, Key decisions and resources are controlled by males. Females who constitute over 90% of the family carers for children affected by life limiting illnesses may not be in position to take effective and appropriate decisions partly due to their subordinate nature and lack of control over family resources. According to study participants, in most families, resources are controlled by males. Violation of this norm might bring about marital stress and tension.

Socialisation of the child was also reported as a major determinant of their ability to participate in decision-making. According to study participants, if the child has been brought up in homes where they are not encouraged to express themselves then they will not talk. Some family carers are too protective. Even when palliative care providers wish to visit the sick child some parents may want to know what the health worker intends to discuss with the child. Palliative care professionals recognise the need to respect what the carers are saying because they are the ones staying with the patients.

Parents require good information about the progression of the disease and the likely implications. They need to understand what is happening (Steinhauser et al, 2000). Goldman & Baum (1994) noted that some time parents have specific treatment preferences such as drip and the others. They want to see if this will make a difference in the life of a patient. Some feel if a patient is taken home and the patient dies, then that is a sign of negligence. Amery (2009) further reported that many cultures do not give children the chance to decide. Parents assume full decision-making power. In some families all decisions are made by the father or the perceived 'bread winner' and in a few cases both parents make decisions but children do not need to talk.

"In Mulago, for instance there are so many patients coming from up country and in most cases they are poor and they rely on the well off relative in Kampala. It is these relatives who make the decisions since they are poor and they do not have money. Whether they like it or not they have to abide by that. That is why for us we have to know who the "Bread Winner" is. In case a bread winner is not even capable of making rational decisions, we call all the persons concerned and we talk to them. We seek their consent whether we can talk to the child and how much the child knows". A palliative care Nurse in Kampala

Health workers also reported the magnitude of the child illness as a key factor for consideration. According to study participants, if the child is very sick, decision-making may be difficult. Decision-making calls for a fully conscious person and mentally sound. In case of mental impairments, decisions are based on professional analysis (Levetown 2004).

In addition to the above list of exceptions, Harrison et al, (1997) recognize the following special circumstances, that may apply in the context of Uganda such as;

*Religious objections*-Conflicts of interest or religious preferences may lead parents to make decisions that may not be in the perceived best interests of the child. The children of Jehovah's Witnesses, particularly those who require an operative procedure that is associated with a risk of significant blood loss, are best considered in a distinct consent process that incorporates the religious views but upholds the rights of the child.

*Emergency care*-When a child is brought to an emergency department by pre-hospital care providers, no parent is in attendance, and the child needs emergency treatment or surgery, most hospitals and operating rooms allow treatment to be initiated under the theory of implied consent for emergency treatment. Aggressive attempts should be made by emergency department personnel to locate the child's parent(s) or guardian, but life-saving maneuvers, including surgical procedures, should not be withheld. Under the circumstance of need for urgent surgery, an institutional requirement may be in place for two or more physicians, generally those who are not involved in the technical procedure, to sign a consent form on behalf of the child, indicating their agreement that a true emergency exists and the proposed surgery is warranted.

*Children of divorced parents*-Many parents are divorced, and custodial arrangements for their child may be complex. If a child's parents are divorced, the custodial parent usually has the authority to make medical decisions on behalf of the child. For new pediatric patients coming to the clinic or office, registration forms should denote with whom the child lives and who has legal custody. At times, the custodial parent may indicate a desire to limit visitation or provision of information to a non-custodial parent.

It is worth noting that, antagonistic parental relationships may interfere with the physician's ability to render appropriate care to the child. Examining written divorce settlements may be



necessary to determine what is legally appropriate. These tasks can be delegated to a member of the hospital legal department if necessary. Unfortunately, a parent may occasionally become offensive, abusive, or aggressive, and the security services of the hospital may have to be involved and/or visitation privileges may have to be restricted or rescinded.

#### **4.13 Challenges of decision-making in children palliative care**

Communication is also a key challenge reported by study participants, especially health professionals. Good care requires one to know the art of communicating with a child. Some health workers do not know how to communicate with children and this complicates the process of offering care and support. In Hospice staff may know how best to handle these patients but then when they go to other places for referral services they may be handled rudely and at the end of the day they get disgusted and may not enjoy the entire care being given and this affects their quality of life.

A study by Hsiao et al, (2007) emphasizes five domains of physician communications that are deemed to be highly salient and influential in quality of care. These included relationship building, demonstration of effort and competence, information exchange, availability, and appropriate level of child and parent involvement. Parents identified coordination of care as another important communication domain.

Study participants highlighted the following issues as characteristics of physicians that were deemed most harmful to satisfying communication; having a disrespectful or arrogant attitude, not establishing a relationship with the family, breaking bad news in an insensitive manner, withholding information from parents and losing their trust, and changing a treatment course without preparing the patient and family.

Similarly, Mark et al., (2004) in their study of parent and physician's perspectives on quality of care for children affected cancer reveal higher parent ratings of physician giving clear information about what to expect in the end-of-life period, communicating with care and

sensitivity, communicating directly with the child when appropriate, and preparing the parent for circumstances surrounding the child's death.

Disclosure was a key concern among family carers. Parents may not want health conditions disclosed and yet the child may need to be briefed about a given health problem. Health and family carers acknowledge the fact that children learn a lot from their peers and may also get tired of taking medications continuously. Depending on one's judgement, disclosure is the only option available. Some carers have had bad experiences with their children due to the fact that their children were not informed about what is happening to them. Carers do admit the fact that children are very observant and inquisitive. Sometimes they ask questions to validate what they already know.

Diagnosis and assessment of pain in children is quite complex as reported by health professionals. This also depends on the age, the ability of the care giver to interact well with the child and the intellectual capacity of the child. When poor assessment is done, the final decision made may be wrong and this affects the quality of life of the child.

Cultural issues such as refusal of blood transfusion by some religious faith such as Jehovah's witnesses may complicate treatment options. Even when you know this child is anaemic, because of religious limitations it might not be possible to help the affected child. The age of a child and legal issues further complicates decision-making. Due to fear of legal implications some decisions may not be made or failure to make certain decisions may result into court cases. This presents dilemma regarding to what extent you can disclose, use informed consent or encourage the participation of the child.

Poverty is another key concern of patients, carers and palliative care team- the parent may want to access some treatment options but due to financial limitations they may fail to make decisions. Treatment options are also expensive for most family. Some families may not easily afford the second line chemotherapy. Dependency is common; some times parents use their children to get hand out such as food, money and other benefits.

The multi disciplinary team involvement is usually bureaucratic and sometimes it is difficult to have a common understanding regarding patient management plan. Different stakeholders may understand the care process at different levels and may have different opinions on how to improve the quality of life. In such cases the parents and children may be left in a state of confusion. It becomes difficult to know whose views to take especially in a moment of life and death. There are many myths and misconceptions about the effectiveness of some of the therapeutic drugs such as chemotherapy.

“There are moments when a colleague may come up with an idea that may not necessarily be relevant but because you have to work as a team, you may need to be accommodative”. A palliative care nurse.

Parents feel distressed about decisions to keep the child in hospital when in actual sense the health workers very well knew that the child is about to die. At the end of it all the parents end up incurring unnecessary transport expenses. Some family members strongly believe in children dying from the hospital. If a parent decides to take the child home and should the child die, the concerned parent is blamed for negligence.

“We had a case of a pastor who had a sick child in the hospital for one month. When he eventually took the child home the community members alleged that he had been to a witchdoctors place. This affected his reputation as a pastor. In order to clear his name, he returned to the hospital and begun taking pictures of the ward where his child was admitted. All this he was doing in order to stay in harmony with the family and community members”. A palliative care nurse in Mbarara.

From the above experience, it can be concluded that sickness of the child does not only concern the immediate family but also the entire community and this has significant social effect on the entire family. There are always blames when something goes wrong with a child. We need to pass on the right information about the illness of a child. You have to be confident about your diagnosis.

## **CHAPTER FIVE**

### **5 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 Introduction:**

This study aimed at exploring decision-making approaches in children palliative care institutions- a case study of hospice Africa Uganda. The study was qualitative, using exploratory design. Data was collected from primary sources using triangulation of methods and findings. This chapter presents the summary of the main findings, conclusions and recommendations for policy and programme implementation.

#### **5.2 Summary of the findings:**

##### **5.2.1 Socio-demographic characteristics of the study respondents:**

The greatest proportion of the study participants were derived from HAU-Makindye, which has more Palliative care team members compared to Little Hospice Hoima and Mbarara. The Kampala programme is relative more stable compared to the other sites.

Palliative care is traditionally perceived as a female responsibility and this partly explains why most of the respondents are female. Children participation by and large is passive and any effort to elicit their active participation requires adequate time and extensive rapport. Unfortunately due to limited time and cultural factors few children could express their views regarding the issues raised in this research. Family carers are mainly female. Again male counterparts focus more on looking for resources to facilitate care. The researcher did not have a lot of opportunities to engage male family carers in this study because they were not readily available.

### **5.2.2 Meaning and experiences with decision-making in children's palliative care:**

Improving the quality of life is the goal of palliative care practitioners at Hospice Africa Uganda. Whether this will prolong life or not is not the main focus. Therefore any action taken or decision made should help in achieving the goal stated above.

Study participants recognise the fact that children are not just little adults. Respondents recognise the uniqueness of children's palliative care compared to adults. The main difference being in approaches and methods used to provide care.

A striking difference was also observed between children in urban and rural settings. Children in urban setting are more assertive compared to the ones in remote setting. Influence of culture is more prominent in rural settings compared to urban settings.

The types of the decisions to be made are many and broad. It is important to note decisions too are made using the principle of holistic assessment. Decisions made arise from the wishes, values and aspirations of the child and the family.

### **5.2.3 Participants in decision-making in Children's palliative care**

Decision-making is perceived as a multi stakeholder responsibility, involving health workers, children, family carers, non health professionals. However the application of the multi-stakeholder approach to decision-making remains a challenge due to the fact that not everyone has the same understanding of the palliative care philosophy. Active participation of participants in decision-making varies, particularly among family carers and children. Palliative care practitioners highly value the role of other care providers. Curative health workers on the other hand are not well versed with palliative care approaches.

Family carers put their trust in health professionals when it comes to palliative care decision-making. Depending on the approaches used, they are happy to be involved in decision-making

process. Most carers would like to have a clear understanding of the patient management plan, diagnosis and prognosis. Female carers could effectively contribute to decision-making if male carers are brought on board right at the start of palliative care for the affected child. Early involvement would minimise socio-cultural and gender impediments to decision-making. However efforts to influence male participation needs to be handled cautiously in order to ensure palliative care is provided with due value for culture of the place.

Capacity of children to participate in decision-making is dependent on factors such as age, level of maturity, family orientation, self esteem and confidence level, approaches used in involving them or enhancing their participation, among others. The longer a child stays on palliative care programme, the more informed they become about their health conditions. Children who attend day care services in particular are more confident and assertive in expressing their feeling and concerns.

#### **5.2.4 Ethical principles for decision-making in children's palliative care**

Study findings indicate high level of awareness of the key ethical principles among palliative care practitioners at HAU. Much as palliative care practitioners are aware of the ethical principles, application of the principles depend on factors such as the level of awareness about the rights of patients and families, level of physical, cognitive and emotional maturity of the affected child, severity of the illnesses especially pain. When a patient is in extreme pain, sometimes their participation or consent on critical decisions may be hard to enforce.

Ethical dilemma is common in areas such as knowing whose view matters in the course of decision-making in children palliative care. Due to socio-cultural influence, the ones whose views matters in most cases is not the person who is with the patient every moment.

Generally, the voices of doctors tend to override the rest of the stakeholders when it comes to treatment or medical decisions. This is a traditional cultural mentality. Palliative care team very much attempt to respect the wishes of the children.

Standard definition of the concept of ‘best interest’ in decision-making does not exist. Palliative care practitioners at Hospice Africa Uganda use indicators such as the clients expressed wishes, expected benefits, consent by the child, health workers professional judgement, acceptability by the patient, anticipated positive change to determine whether a decision is in the best interest of the child and their family members.

#### **5.2.5 Factors that influence decision-making in children’s palliative care**

Several factors influence the process of decision-making. These include; the nature and severity of the illnesses, the attitude of care providers, family power relations, the willingness of the family members to participate in decision-making, financial position of the family carers, the level of communication skills and expertise in dealing with children and their families. The number of participants involved in decision-making approaches and their levels of understanding of the health conditions of the affected child.

Good communication is recognized as an essential component of patient –practitioner partnership. Hospice Africa Uganda, palliative care practitioners believe communication with children require patience and adequate time in order to establish effective rapport. Children do not communicate the way adults do. Some of them communicate through songs, games, story telling, drawings etc. it was observed that children are intelligent regardless of their age.

### **5.3 Conclusions of the study**

#### **5.3.1 Meaning and experiences with decision-making in children's palliative care:**

Meaning and experiences with decision-making vary from individual to individual or location to location. However, palliative care teams at HAU sites endeavor to incorporate the affected child's, and where appropriate, family choices, values, beliefs and goals in decisions making. Where appropriate, early discussion of diagnosis and prognosis and of the potential benefits, burdens, and risks associated with various therapies and with the refusal of therapy should be done. This helps decision makers to uphold the ethical principles identified in this study.

#### **5.3.2 Participants in decision-making in Children's palliative care**

Decision-making in children's palliative care is best done in partnership. It involves multiple stakeholders- health and non health workers. Decisions must be in the best interest of the child. Family carers to a great extent play an important and integral role in decision-making, working with the palliative care team. Family carer's participation can be enhanced if palliative care teams appreciate the role they play in improving the quality of life of the affected child.

The assumption that parents best understand what is in the interest of their child is usually sound. However situations may arise in which the parent's distress prevents them from attending carefully to the child's concerns and wishes. It is helpful and respectful of the child to affirm the parent's responsibility for the care of their child while allowing the child to exercise choice in measure appropriate to his/her level of development and experience of illness and treatment.

#### **5.3.3 Ethical principles for decision-making in children's palliative care**

Ethical principles that provide guidance in the care of adults are insufficient in the context of caring for children. Issues related to consent, disclosure of information, capacity assessment, treatment decisions and bereavement are more complex in children's palliative care. The adult model presume the patient is autonomous and has stable sense of self, established values and mature cognitive skills. These areas are under developed in children.



Much as there is no candid definition of the concept of “ Best Interest” , it is important to ensure that decisions made should reflect values, wishes and aspirations of the affected children and their families. Factors that influence decision-making in children’s palliative care

#### **5.3.4 Factors that influence decision-making in children’s palliative care**

Many factors influence decision-making in children palliative care. These include type of disease, prognosis, intensity of treatment and potential adverse effects, family issues, socio-cultural factors, goals, values and beliefs, and personal priorities. Socio-Cultural factors, in particular have significant Influences on decision-making in children. It is very important to recognise the diversity of cultural and religious perspectives relevant to decision-making in children’s palliative care. Special attention is needed for issues such as; the preferred place of treatment, whether to communicate about the diagnosis and prognosis.

Children with chronic or terminal illnesses may have experiences that endow them with insights and maturity beyond their years. Allowing even young children to make decisions about simple matters facilitates the development of skills that they will need to make more complex decisions later on.

## **5.4 Recommendations from the study**

There is a dire need to improve communication skills of children palliative care practitioners. Most study participants appreciate the need to involve children in decision-making but lack the necessary skills of communicating with them. As a result respondents were in most cases quick to use the variable of age to justify why they do not involve young children in the process of decision-making.

Health practitioners oriented to curative approach of care need to be educated about the fundamentals of palliative care. This will help in positively influencing their perception and attitudes.

The awareness raising needs to be extended to family carers as well. Family carers, especially the males (heads of the families) need to be educated about the roles and also the need to empower their wives to effectively contribute to decision-making process. For husbands and wives to contribute to decision-making all of them need to be at the same level of understanding about the child's health conditions.

Palliative care practitioners need to appreciate socio-cultural differences. The fact that children in certain locations do not assertively express themselves does not mean they have nothing to contribute to the process of decision-making. Child friendly approaches and adequate time to build rapport with the affected child can make a big difference.

Minimal involvement of male carers does not necessarily mean they care less for the affected child. It could be more of gender role segregation, with positive intentions.

Interventions which have socio-cultural implications should be handled cautiously. As much as possible the positive aspect of the culture should be brought to light and opportunities for good care maximised. Change of negative aspects of culture will require adequate time and this could be through awareness creation among stakeholders in children's palliative care and continuous mass education.

Children's palliative care practitioners should be provided with education and support in cultural awareness to enable them to care for all children and family members in a sensitive and culturally appropriate manner. This includes timely access to support personnel such as trained translators, indigenous community members, and religious advisers.

Integration of children's palliative care into curative care in hospitals and health facilities is urgent since there are very few "stand alone" children's palliative care services within Uganda. Building constituencies for children's palliative care is very important. It is worth noting that cancer is no longer a disease for adults, the rich or developed countries. It is all over regardless of age and socio-economic conditions. a shared understanding of palliative care principle is important. Value for children and their families is important. As earlier noted, the affected child is always the "expert" there is need to consider their views, aspirations in decision-making process. Shared decision-making is effective way to promote quality of life, if done well.

More time needs to be allocated for children's palliative care specialists since they deal with special group of patients, who may take long to share their feelings and build rapport with care providers.

Further research is recommended in the following areas:

- Influences of socio-cultural factors on children's palliative care decision-making.
- Approaches for empowering female carers to effectively contribute to decision-making in children's palliative care.
- Dealing with challenges of working with multi disciplinary teams in providing children's palliative care services.
- Effective participation of minors/infants in palliative care decision-making
- How to integrate children's palliative care within adult's palliative care.

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## Introductory Letter

**MAKERERE**

P.O. Box 7062,  
Kampala, Uganda  
Cables: MAKUNIKA



**UNIVERSITY**

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DEPARTMENT OF SOCIAL WORK AND SOCIAL ADMINISTRATION

10 March 2009

Dear Sir/Madam,

Re: M.A Research

This is to introduce to you Nimungu Alfred Duku a graduate student on our Masters Programme of Social Sector Planning and Management (MA.SSPM). He/she is undertaking his/her research titled:

DECISION MAKING APPROACHES IN CHILDREN'S  
PALLIATIVE CARE INSTITUTIONS!- A CASE OF  
HOSPICE AFRICA UGANDA

His/her research proposal has been approved by the Departmental and Faculty of Social Sciences Higher Degrees Committee.

The purpose of this letter is to request you to give him/her the necessary assistance to enable him/her accomplish his/her research.

Thank you very much.

Yours sincerely,

David Kyaddondo (Ph.D)  
COORDINATOR, (M.A SSPM)



## Appendix (1)

### KEY INFORMANTS INTERVIEW GUIDE

#### Bio Data:

Name of respondent (Optional)	
Title of Respondent:	
Profession:	
Age:	
Sex:	
Work Place:	

1. What is the meaning of palliative care with regards to children affected by HIV/AIDS and or Cancer?
2. What are the unique features of children's palliative care compared to adult palliative care?
3. What does decision-making mean in the context of children's palliative care?
4. What Decisions Need To Be Made?
5. What principles are used when making decisions for Children in need of Palliative Care services? What has been your experiences in application of the mentioned principles?
6. How can you ensure that decisions are made in the "best Interest" of the affected child?
7. What does "Best interest" of the affected child mean in palliative care practice?
8. What major factors influence decision-making for children in need of palliative care?
9. Who is Involved in Decision-making in children's palliative care and what special contributions do the above mentioned persons in children's palliative care decision-making?
10. How do we assess the capacity of the affected child to participate in decision-making?
11. How can one promote a child's participation in decision-making?
12. What circumstances necessitates designation of a Substitute Decision-maker other than the immediate family members?
13. What categories of people have you been using as substitute decision makers and why them in particular?
14. What has been your experience in using substitute decision makers?
15. What would you consider to be the unique and major challenges of decision-making during the care of children with life-limiting or life-threatening illness?
16. How do we work through Conflict especially when the parties involved are not in agreement over the palliative care decisions made?

## Appendix (II)

### IN DEPTH INTERVIEW GUIDE

#### BIO DATA:

Name of respondent (Optional)	
Title of Respondent:	
Profession:	
Age:	
Sex:	
Work Place:	

#### PART I: MEANINGS AND EXPERIENCES WITH DECISION-MAKING

1. What is the meaning of palliative care with regards to children affected by HIV/AIDS and or Cancer?
2. What are the unique features of children's palliative care compared to adult palliative care?
3. What does decision-making mean in the context of children's palliative care?
4. What Decisions need to be made in children's palliative care?
5. What are some of your experiences with decision-making in children's palliative care?

#### PART II: STANDARDS/PRINCIPLES FOR CHILDREN'S PALLIATIVE CARE DECISION-MAKING

6. What principles are used when making decisions for Children in need of Palliative Care services? What has been your experiences in application of the mentioned principles?
7. How can you ensure that decisions are made in the "best Interest" of the affected child?
8. What does " Best interest" of the affected child mean in palliative care practice?
9. What do you use to determine the capacity t the affected child to participate in decision-making?
10. What is the best way of involving the affected child in decision-making?

### PART III: FACTORS THAT INFLUENCE DECISION-MAKING IN CHILDREN'S PALLIATIVE CARE

11. What factors influence children's palliative care decision-making?
  12. What factors influence decision-making by family members of affected child?
  9. What are some of the Parental perspectives on their involvement in decision-making?
  - 
  10. What information might you provide to patient/families so that they can make informed decisions about Palliative care interventions?
  11. What are the major socio cultural issues that influence children's palliative care decision-making?
- 

12. How do socio- cultural issues influence decision-making in children's palliative care?
13. What approaches could be used to discussing cultural issues with families

### PART IV: PARTICIPANTS IN CHILDREN'S PALLIATIVE CARE DECISION-MAKING

14. Who is Involved in Decision-making in children's palliative care and what special contributions do the above mentioned persons in children's palliative care decision-making?
15. How do we assess the capacity of the affected child to participate in decision-making?
16. How can one promote a child's participation in decision-making? What value do you see in involving children in discussions about their care?
17. In what ways might the families be involved in the process of decision-making?
18. Under what circumstances family members might be excluded from the process of decision-making?
19. What are some of your experiences in involving family members decision-making?
20. What circumstances necessitates designation of a Substitute Decision-maker other than the immediate family members?
21. What categories of people have you been using as substitute decision makers and why them in particular?
22. What has been your experience in using substitute decision makers?

### PART V: CHALLENGES OF DECISION-MAKING IN CHILDREN'S PALLIATIVE CARE

23. What would you consider to be the major challenges of decision-making in children's palliative care?

24. What are the major Challenges to building consensus among people participating in children's palliative care decision-making?
25. What are the major causes of disagreements during decision-making process?
26. What strategies might be used to build consensus in decision-making in the “ best Interest” of the affected child?

## Appendix (III)

FOCUS GROUP DISCUSSION GUIDE
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Date and Location\_\_\_\_\_

FGD Team \_\_\_\_\_

1. What is the meaning of palliative care with regards to children affected by HIV/AIDS and or Cancer?
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3. What does decision-making mean in the context of children' palliative care?
4. What Decisions Need To Be Made?
5. What principles are used when making decisions forf Children in need of Palliative Care services? What has been your experiences in application of the mentioned principles?
6. How can you ensure that decisions are made in the "best Interest" of the affected child?
7. What does " Best interest" of the affected child mean in palliative care practice?
8. What major factors influence decision-making for children in need of palliative care?
9. Who is Involved in Decision-making in children's palliative care and what special contributions do the above mentioned persons in children's palliative care decision-making?
10. How do we assess the capacity of the affected child to participate in decision-making?
11. How can one promote a child's participation in decision-making?
12. What circumstances necessitates designation of a Substitute Decision-maker other than the immediate family members?
13. What categories of people have you been using as substitute decision makers and why them in particular?
14. What has been your experience in using substitute decision makers?
15. What would you consider to be the unique and major challenges of decision-making during the care of children with life-limiting or life-threatening illness?
16. How do we work through Conflict especially when the parties involved are not in agreement over the palliative care decisions made?

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THANK YOU FOR THE PARTICIPATION!