

ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF ALLIED HEALTH SCIENCE
DEPARTMENT OF NURSING AND MIDWIFERY

ASSESSMENT OF NURSES KNOWLEDGE PRACTICE AND ASSOCIATED
FACTORS TOWARDS PEDIATRICS PALLIATIVE CARE OF NURSES
WORKING AT SELECTED HOSPITALS IN ADDIS ABABA, ETHIOPIA

BY:

ALEMNESH MANDESH

ADVISOR:

ATO BIRHANE GEBRE KIDAN

(Assistant Professor)

A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF ADDIS ABABA
UNIVERSITY COLLEGE OF HEALTH SCIENCES, SCHOOL OF ALLIED HEALTH
SCINECES IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF
MASTER OF SCIENCE IN CHILD HEALTH NURSING IN THE DEPARTMENT OF
NURSING AND MIDWIFERY.

JUNE 12, 2014

ADDIS ABABA , ETHIOPIA

Acknowledgement

First I would like to extend my heartfelt thanks to my advisor, Ato Birhne G/kidan Assistant Professor at AAU for his unreserved guidance and constructive comments and suggestions of unfailing moral support in caring out research project and keen interest to read the report by devoting his precious time and constructive criticism which helped me significantly till the end of research work.

I would like to acknowledge and wish to express my gratitude towards Addis Ababa University, College of Health Sciences, Department Of Nursing and Midwifery for giving me the opportunity to enroll in this program and Graduate studies, financial support without which this project would have been impossible.

My special thanks also go to Ato Fekadu Aga MCN and lecturer in AAU for his encouragement and continuous support, advice and supply of different reference materials.

I am great full to hospital medical directors, administrators, matrons, and nurses who participated in this study

I would like to acknowledge Dr Wondemageghu Tigenhe and sister Aster Syuom for their support and contribution of materials.

Finally, I would like to thank my husband Ato Muluneh Sewnetie and all my families for their significant patience and support.

List of abbreviations

ABCDE :A –Ask about pain regularly

B- Believe the patient and /or family’s report pain

C- Choose appropriate pain approaches and treatment option

D- Deliver interventions in a coordinated and timely fashion

E- Empower patients and their families

ALERT- All African Leprosy Rehabilitation and Training Center

APCA –African Palliative Care Association

CHiPPS - Children’s Project on Palliative Care /Hospice Service

CSSD- Central sterilization supply department

FLACC- Face, Leg, Activity, Cry, Consolability

HIV- Human Immunodeficiency Virus

PCQN- Palliative Care Quiz for Nurses

PC- palliative care

PPC-Pediatrics palliative care

POS - Palliative Outcome Scale

SSA- Sub Saharan Africa

WHO –World Health Organization

Table of Contents

<i>Title</i>	<i>Page</i>
Acknowledgement -----	i
List of abbreviations-----	ii
Table of content -----	iii
List of table-----	vi
List if figures-----	vii
Abstract -----	vii
Chapter I Introduction -----	1
1.1 Back Ground-----	2
1.2 Statement of the Problem -----	5
1.3 Significance of the Study -----	7
Chapter II Literature Review -----	8
Chapter III Objective of the Study -----	21
3.1 General Objective-----	21
3.2 Specific Objective -----	21
Chapter IV Material and Method -----	22
4.1 Study Area -----	22
4.2 Study period-----	23
4.3 Study Design-----	23
4.4 Source Population -----	23
4.5 Study population -----	23

4.6 Eligibility criteria-----	23
4.6.1 Exclusion Criteria -----	23
4.6.2 Inclusion Criteria-----	23
4.7 Sample Size Determination_sampling procedure-----	24
4.7.1 Sample Size -----	24
4.7.2 Sampling technique-----	24
4.7.3 Proportional allocation -----	26
4.8 Variables -----	29
4.8.1 Independent Variable -----	29
4.8.2 Dependent Variable-----	29
4.9 Method of Data collection -----	30
4.9.1 Quantitative Data -----	30
4.9.2 Qualitative Data -----	30
4.10 Pre test-----	30
4.11. Data Collection Instrument -----	30
4.11.1 Data Collection -----	31
4.11.2 Data Processing -----	31
4.11.3 Quantitative Data -----	31
4.11.4 Qualitative Data -----	32
4.11.5 Data Quality control-----	32
4.12. Statistical analysis -----	32
4.13 Ethical Consideration -----	32
4.14 Operational Definition -----	33

4.15 Dissemination of Result	33
CHAPTERT V RESULT	34
5.1. Socio-Demographic characteristics	34
5.2. Nurses knowledge towards pediatric palliative care	36
5.3. Practice of nurses towards pediatric palliative care.....	38
5.4. Association Between socio demographic variable and nurse’s knowledge towards palliative care.....	40
5.5. Association between socio demographic variable and nurse’s knowledge- aspect of practice towards palliative care	42
CHAPTER VI DISCUSSION	44
CHAPTER VII QUALITATIVE DATA.....	52
CHAPTER VIII STRENGTH AND LIMITATION	58
STRENGTH.....	58
LIMITATION	58
CHAPTER IX CONCLUSION AND RECOMMENDATION	59
CONCLUSION	59
RECOMMENDATION	59
REFERENCES	62
LIST OF ANNEXES.....	66
ANNEX ONE.....	66
Part one Information sheet and consent English version.....	66
Part two information sheet and consent Amharic version	70

ANNEX TWO

Part one Socio Demographic Data- English -----	72
Part two Socio Demographic Data Amharic-----	74
Part three Questionnaires knowledge' (PCQN) English-----	76
Part three Questionnaires' knowledge Amharic -----	77
ANNEX THREE -----	78
Part one knowledge aspect of practice of nurses, English-----	78
Part two knowledge aspect of practice of nurses, Amharic-----	81
ANNEX FOUR -----	83
Part one Qualitative interview guide English -----	83
Part two Qualitative interview guide Amharic-----	83

List of tables	page
Table 1. Socio Demographic Characteristics of nurses At Selected Hospitals at Addis Ababa ,Ethiopia ,March –June 2014. (N=252)	35
Table 2. Distribution of nurse’s knowledge towards pediatric palliative care in selected hospitals at Addis Ababa, Ethiopia, March – June 2014	37
Table 3. Practice of nurses towards palliative care at selected hospital in Addis Ababa, Ethiopia, March – June 2014	39
Table 4. Association between some socio demographic variables and nurses knowledge towards pediatric palliative care at selected hospitals in Addis Ababa, Ethiopia, March – June 2014	41
Table 5. Association between some socio demographic characteristics and nurses knowledge aspect practice towards pediatric palliative care at selected hospitals, in Addis Ababa, Ethiopia, March – June 2014	43

List of figures	page
Figure I: Conceptual frame work-----	20
Figure II: Schematic representation ----- of sample procedure	28

ABSTRACT

Back ground:

To provide quality pediatric palliative care at the end of life or with life threatening illness, nurse must have good knowledge and practice about pediatric palliative care . Palliative care is approach that improves the quality of life for children and their families facing the problem. Palliative care is new and specialized field for nurses, very little is known about the type of services offered and the readiness of the nurse to provide palliative care. Knowledge and competences of optimal pain assessment and management at the end – of life enhances nurse’s practical knowledge. Knowledge of palliative care is essential for nurses, especially in pediatrics’, where palliative care is less common than with adults.

Objectives: Assessment of nurses’ knowledge practice and associated factors towards pediatrics palliative care of nurses working at selected Hospitals in Addis Ababa, Ethiopia.

Material and methods: A cross sectional quantitative study design was carried out on 252 nurses working in selected hospitals of Addis Ababa. For qualitative study FGD was conducted in three groups, one group contains 6-8members. The study was conducted from November to June 2014. Five governmental and two nongovernmental hospitals was selected. These hospitals selected because they admit children of different age for care and treatment. Palliative Care Quiz for Nursing (PCQN) and practical questions tools from African palliative care Association /palliative outcome scale for Africa was used. EPI-INFO and SPSS soft ware statistical package were applied for data entry and analysis .P-value less than 0.05 were considered as statistically significant.

Result: The response rate was 252 (98.8%) of the total 249 respondents. Out of total study participants only 37(14.8%) had good knowledge toward pediatric palliative care. Bachelor and Master level of education were significantly associated with knowledge of pediatric palliative care. Training on palliative was significantly associated with knowledge of nurses towards palliative care. Concerning their knowledge aspect practice more than half 243(97.5 %) of the respondent had poor knowledge aspect of practice towards pediatric palliative care and 190(76.3%) initiate pediatric palliative care discussion to the family during diagnosis.148(59.4%), inform to the family their child's terminal stage illness. Age, sex year of working experience pediatric ward had significant association with knowledge aspect practice of pediatric palliative care.

Conclusion and Recommendation

The finding of this study show nurses participated in this study had poor knowledge (85.2 %) and knowledge aspect practice (97.5%) had poor towards pediatric palliative care. Therefore pediatric palliative should be integrated in to the national health policy and incorporate in nursing curriculum .Training should also be delivered in this field to nurses in hospital.

Key words: Addis Ababa, knowledge, nurse, palliative care, pediatrics and practice.

CHAPTER ONE

Introduction

1.1 Background

Palliative care is approach that improves the quality of life for children and their families facing the problem associated with life threatening illness through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (1). Palliative care is the science and art of lessening physical, psychological, emotional and existential suffering (2). Palliative care can benefit patients and families whether the over goals of care is to cure prolong life, maximize the quality of the life that remains, or ease the pain of bereavement (3). Thus, palliative care is provided concurrently with, or as an alternative to, life sustaining medical intervention (4).

Palliative care is necessary for four categories of illness. First palliative may be appropriate for illness in which curative treatment or treatment to prolong life is available but may fail. Second, palliative care beneficial for conditions needing intensive treatment for an extended period of time to prolong quality of life. Third, palliative care is used in progressive conditions that exclusively require palliative care treatment from point of diagnosis. Finally, palliative care can benefit those with conditions that involve non progressive disability and cause the child to be susceptible to other health complications (5). The aim is to enhance quality of life and help to maintain independence from life treating diseases as long as possible (6).

According to W H O, definition of Palliative Care for Children represents a special, though closely related field to adult palliative care. W H O's definition of palliative care for children and their families is; the principles apply to other pediatrics chronic disorders (7). Palliative care for children is the active total care of the child's body, mind and spirit, and also involves

giving support to the family (8). It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease (9).

Palliative care began with hospice movement. Hospices were originally places of rest for travelers in the fourth century. In the 19th century a religious order established hospices for dying in Ireland and London. The modern hospice is a relatively recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher's Hospice in 1967. It was founded by Dame Cicely Saunders, widely regarded as the founder of modern hospice movement (10).

Children's Hospital International was established in 1983 to promote palliative and hospice services throughout the world, and the Initiative for Pediatric Palliative Care was established as an educational and quality improvement effort to promote family-centered care for children at the end of life in 27 countries. Such efforts are inspiring, but more effective pediatric palliative care that is sensitive to the ethical, cultural, spiritual, and age-appropriate needs of dying children is needed throughout the world (6).

In recent years, there has been an increased recognition of a global health need for palliative care (9). Palliative nursing care in pediatrics is when a patient has an illness, multiple health care interventions may be put into action to enable the children to overcome the illness. In chronic illnesses, and however, this is not enough. A child may need not only a solution to correct the illness, but care to help in dealing with illness and its effect on a day to day basis (10).

Palliative care and hospices care are two terms that are often used interchangeably; however, there is a distinction between the two. Though a part of palliative care, hospice care support and care for the patient in the final phase of incurable illness. Hospital palliative care teams in Africa are mainly nurse led with few teams having both nurses and doctors (11). Hospital palliative care programs provide high quality, comprehensive care for seriously ill patients and their

families. International council of nurses supported that nurses have a unique and primary responsibility for ensuring that individuals at the end of life experiences a peaceful death because much of pediatric palliative care is nursing care (12). Hospice care may specifically be implemented in the last six months of life. Palliative care on other hand begins at the point of diagnosis. It is not focused on death or dying process of the patient, and neither post pone or accelerate death. Instead, palliative care involves a multi-disciplinary approach at helping the patient live life to its fullest potential. It also aims to support bereaved families so they can remain intact and functional (13).

Palliative care is flexible in that it can be provided in hospitals, community health centers, and tertiary care facilities, and even in the patient's home (3).

Public palliative care or health-promoting palliative care is concerned with building public policies that support dying, death, loss and grief; create supportive environments; strengthen community action and allow people to develop personal skills in these areas (10). Palliative medicine can also help manage pain or other symptoms associated with cancer and its spread not for chronic illness (14).

Although more than half of cancer children live in developing countries, only about 10% of cancer control resources are available to them. Palliative care services are unavailable to 8 or 9 of every 10 children who need these services in developing countries (11). Most families live in rural communities with limited or nonexistent access to health care services. Families are taught to seek medical attention for signs and symptoms of infectious illnesses, such as fever chronic disease. Thus, signs and symptoms of cancer in a child are often overlooked until the disease is too far advanced to cure in such cases community or home based care not available (12). Pediatrics palliative care is not about dying, rather it is about helping children and families to live to fullest while facing complex medical condition (13).

Much progress has been made in the provision of palliative care across sub-Saharan Africa, however much still remains to be done, particularly in the area of children's palliative care (14). Palliative care provision within Sub-Saharan Africa (SSA) remains for many, a relatively new concept. Ethiopia lacks pediatrics palliative at large (1).

Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes (15).

Nurses spend more time with patients to give care. Knowledge and competences of optimal palliative care, pain assessment and management at the end – of life enhances nurse's practical knowledge. The vision, of developing quality at the end –of- life care demand for nurses to be knowledgeable in the concept of perception of pain assessment and management in palliative care (16).

1.2 STATEMENT OF THE PROBLEM

Infant / child mortality rate is extremely high in the face of a significant disease burden especially from HIV / AIDS and cancer as well as from chronic diseases, the humane and effective care of children affected by progressive, incurable and life-limiting disease. To enhance children's quality of life and help them with any changes and end-of-life issues in their preferred place of care (17). The vast majority of children with chronic and communicable disease live in countries with far fewer resources than are available in high-income countries. In every way, from adequate resource to access to affordable care and palliative services, children in low-income and middle-income countries are in greatest need (18). Lack of dissemination of knowledge of the basic principles of pain assessment and relief a palliative pain care remains a problem in both developed and developing countries (19). Comprehensive international guidelines for nurses and other healthcare providers do not exist. It has been estimated that two-thirds of adults and children who need palliative care live in developing countries that have less than 10% of the world's resources .Children's Hospice International estimates that globally, 7 million children could benefit from palliative care (13). Recent systematic review identified that out of 43 European countries, 33% had no known pediatric palliative care activity, and in just 12% of countries was pediatric palliative care reaching a measure of integration with mainstream service providers (14)

Pain, particularly chronic pain, is a major treat to quality of life worldwide (11).Millions of people around of the world are in immediate need of pain management. This is especially true not only for children with cancer and HIV/AIDS but also for million people suffering injuries from road accident ,violence acts of war ,child birth and after surgery(12).Proper pain assessment is generally considered a prerequisite for proper pain treatment, but despite dedicated efforts, studies demonstrate that pain still is not adequately assessed (10).

Children who die of cancer have substantial suffering, and attempts to control their symptoms are often unsuccessful (14). Greater attention must be paid to palliative pain assessment and management for children who are dying of chronic long standing diseases. The aim of this study is to assess nurse's knowledge, and practice on pain assessment and management to children with cancer and chronic diseases (16). Studies have documented that nurses and other health care professionals are inadequately prepared to care for patients in palliative care. Several reasons have been identified including inadequacies in nursing education, absence of curriculum content related to pain management, and knowledge related to pain and palliative care (20). To describe the course of terminal care provided to hospitalized children in terms pain management, and pain assessment (21). It is important that nurses have on insight on knowledge pediatrics palliative care, pain assessment and management of Life-limiting / life-shortening conditions such as cancer and chronic diseases (23). Inadequate pain management has been shown to affect patient outcomes by potentially increasing hospital length of stay and delaying recovery research showed that up to 81% of hospitalized children report moderate to severe level of pain, and that nurses administer only 23% to 43% of analgesics ordered (34).

1.3 SIGNIFICANT OF THE STUDY

Child mortality morbidity rate is under question, because children are vulnerable to disease, which encounter their life. Palliative care is one of the health care approaches that improve the quality of life and their families facing the problem associated with life threatening illness (21). Lack of knowledge and competence of nurses to give palliative care to children and incapability to use children pain assessment scale and management worsen severity and distressing symptoms of the disease (3). Nurses tend to spend more time with children with chronic diseases than any other health team members. It is the nurse who performs many interventions for pain relief or further individualizes for the child whose interventions prescribed or performed by others. It is also the nurse who is most likely to be in a position to evaluate the effectiveness of pain management plan and initiate any necessary changes (19).

The finding of this study may contribute to a better understanding of nurses' Knowledge, of pain assessment and management, as well as improves the standard of practice of palliative and end -of- life care. It is helpful to nurse educators to give great emphasis of what palliative nursing care and end -of -life care and can be used to support and design program development for staff nurses and nursing students (22).

In addition, it is helpful for further research, and provides insight to nurse administrator who is seeking to improve pediatrics palliative care services, family satisfaction in the study hospitals (11). This could also serve as the base line and be helpful for improving the palliative care nursing service in Ethiopia. It is helpful to develop curriculum to train nurse student as field of specialty. Study question will be "do nurses working in pediatrics ward of study hospitals able to give pediatrics palliative care specifically pain and symptom control to the children with life threatening like cancer and chronic disease or not? "

CHAPTER TWO

2.1 LITERATURE REVIEW

Palliative care is the science and art of lessening physical, psychological, emotional and existential suffering (3). Palliative care can benefit patients and families whether the over goals of care is to cure prolong life, maximize the quality of the life that remains, or ease the pain of bereavement. Thus, palliative care is provided concurrently with, or as an alternative to life sustaining medical intervention (4). Palliative care is necessary for four categories of illness.

First palliative care may be appropriate for illness in which curative treatment or treatment to prolong life is available but may fail. Second, palliative care is beneficial for conditions needing intensive treatment for an extended period of time to prolong quality of life .Third, palliative care is used in progressive conditions that exclusively require palliative care treatment from point of diagnosis. Finally, palliative care can benefit those with conditions that involve non progressive disability and cause the patient to be susceptible to other health complications (17).

Palliative care is an emerging nursing specialty and is developing a dedicated spot in the field of pediatrics. Pediatrics palliative care differs from adult care in that the care is child focused and family centered. Family plays a more integral role in pediatric palliative care (18). The nurse working with these children must also be knowledgeable regarding the different stages of growth and development that children go through. Nursing care should be patient specific to child's physical growth and cognitive development (3).

As a specialty, palliative care focuses on quality of life and symptom management for patients who are living with chronic and life threatening diseases. In pediatrics advances in health care mean that many children are living longer with these conditions and could benefit from services that focus on quality of life and superior symptom management (19). Palliative care

can be provided concurrently with curative therapies and is philosophically similar yet distinct from hospice services (24).

Analysis indicated the concept of palliative care is poorly understood by health professional and parents(25). Many families are affected emotionally, financially and physically by the burden of caring for children with life threatening or conditions requiring complex care at home (30).

A child's life-limiting illness has a profound effect on all dimensions of family life. Caring for a chronically sick or dying child is an enormous and complex task. Families in these care situations feel the effects of the child's illness emotionally, psychologically, and financially. When a child dies, it is one of the most traumatic events a family can experience, with lasting physical and emotional effects. Ensuring families receive the appropriate care prior to and following their child's death is essential to their long term well being. Pediatrics palliative care is not about dying; rather it is about helping children and families to live to their fullest while facing complex medical conditions. (21).

The focus of pediatric care has traditionally been limited to investigation, diagnosis, treatment and cure .More recently there has been an increased awareness of the need for coordinated and comprehensive palliative and supportive care for children with life –threatening illness and their family (30).

Tens of millions of children worldwide are affected by life threatening illness such as HIV/AIDS and cancer and chronic disease congenital disabilities, which causes them and their families' great suffering and economic hardship (22). The majority of cases occurs in the developing world where quite often little accessibility to prompt and effective treatment for chronic disease is available (23). More than 70% of all children deaths occur due to different reasons in low – to middle income countries. Each year approximately 166,000 children under the age of 15 are diagnosed with cancer worldwide. By 2030, the developing world is

expected to bear 70% of the global cancer burden. Poverty continues to be linked to cancer in the developing world, with cancers having already progressed to an incurable stage in 80% of patients by the time of detection and diagnosis (4).

Provision of pediatric palliative care around the world is scant. Study suggest that 65.6% of countries around the world with no known pediatric palliative care activities (26). Education is an essential component of the development of palliative care. All health care professionals need to be able to provide appropriate palliative care and therefore need to be trained to provide the highest possible standards of care in order to meet the needs of the patient and their family (27)

There are of course many reasons for this such as finances, lack of trained professionals, and a lack of general awareness by the public or policymakers. World Health Organization propose the use of integrated model of palliative and curative care for children and families from the time of diagnosis throughout the illness trajectory to allow the child and family to benefit from both philosophies of care (30).

In United States it has been estimated 30,000 hospices and few about 10% palliative care for children, that 13.9% of all children are living with a chronic health condition. The majority of these children are suffering from mild chronic health conditions, with only 2% of children suffering from major or extreme levels of disability (33). Palliative care can be provided not only to children who are near the end of life, but also to children with these chronic, life-limiting conditions, even when curative treatments are ongoing. According to the Children's Project on Palliative/Hospice Services (ChiPPS), approximately 8,600 children are eligible for pediatric palliative care services on any given day, and palliative care may be an appropriate model of care for 1.5 to 2 million children living with life-limiting disabilities and illnesses(30).

The available registry data in Tanzania has revealed that 11.5% of all malignant tumors recorded in the cancer registry were in children aged 0–14 years. Around 36% of cancers in Africa are infection related, which is twice from global average. This reflects the challenge of infectious disease (particularly of HIV), and that many cancer patients have underlying HIV infection. Study provides a thorough and systematic appraisal of the evidence of the need for palliative care for children in sub-Saharan Africa, and makes a comprehensive, care providers, donors and policy-makers that all those children who need it have access to palliative care and can live with their illnesses, free from pain, supported with their families, and with the best quality of life possible (9). Of the 53 African countries 81.1% were defined as no known palliative care provision for children .Ethiopia is among those countries .Only 1.9% had evidence of broad palliative care provision for children with the availability of training and focused plans for development of service .Africa is the second to Oceania in the height percentage of countries with no known palliative care provision for children(40).In South Africa approximately 19879000 children live 397,580 of them need palliative which accounts 20 % .South Africa presently the only country in the region with pediatric group within their national association, this has led to the development of an extensive network of children palliative care program in all provinces of the country (4).

The role of physician in providing palliative care to children with cancer has been well described in the literature, yet relatively little is has been written about the unique role play on palliative team role (18). Nurses play a key role on the palliative care team. They often bring cohesion and care coordination to multidisciplinary effort (19). Nurses are often the first to identify the suffering needs of the child. They are present at bed side or in the clinic for extended period time and, have thus unique opportunities to assess and explore child and family needs. This prospective place those in a vital position to facilitate care directed toward the relief of suffering and implementation of palliative care (25).

Every day children around the world die from a variety of causes such as malnutrition, accidents, and complications of birth, AIDS, and cancer. No matter what the causes or circumstances, a child's death always results in heartache, grief, and suffering for families and communities (20). An important point to recognize in palliative care is that it is not an alternative method of care, but instead, a method of care that can co-exist with curative treatments to provide children and families with the best possible treatment (30).

Palliative care is the part of the continuum of care from the time a child is diagnosed with life-threatening illness, such as HIV/AIDS, cancer long standing chronic diseases, until the child dies and beyond –bereavement care. Palliative care includes interventions both preventive and reactive –to improve the quality of life for patients and families. These interventions will prevent and treat problems associated to address wide variety medical and psychological issues (31).

A cross sectional study on factors predicting nurses' involvement of the Palliative Care on 272 participants was carried out involved in the study from different intensive care unit of pediatrics department. 40.0% of respondent have knowledge to give palliative care to children. It is team approach to address the need of children and the family. Some of them lack awareness & knowledge when palliating children, others respond hard to see dying children. Nurses spend the most time in direct care activities with children and their family members managing physical, psychosocial, emotional, symptoms yet many nurses feel anxious and unprepared to care for palliative children. (13).

Other study conducted in Germany (2010) using distributed questionnaires and interview to 293 Pediatrics Palliative Home Care ,about their own practice of giving palliative home care to children with chronic illness .Majority of respondents was nurses they reveals as palliative care is their profile ,but intervention was time restricted(40.7%).Having financial burden to

give care (31, 6%). Holding, responsibility to give care without team support (31.1%). Having lower perception to give pediatric palliative care (26.6%). Lack of experience and practice obstacles can be reinforced by emotional barrier. Many do not feel comfortable with the care for dying children. They need to access other specialists in pediatric palliative care consultation (12). Research indicates among cancer patients, religion and spirituality are positively associated for better quality of life, psychological adjustment and wellbeing 34% of chronically sick patient gets spiritual service from 61% of nurses, 21% of dying children served by 80% of staff nurses (6).

Pain is the primary concern of families and children. It is a subjective experience. Pain is defined as unpleasant sensory and emotional experiences associated with actual or potential tissue damage, or described in terms of such damage. (4) Pain is a common reason for pediatric patients to present to hospital. Pain can have a direct impact on health outcomes and, if uncontrolled, may have a diverse effect on all areas of life. This is because pain is not only a sensory perception but has emotional, cognitive, and behavioral components, which also need to be recognized (25).

The impact and perception of pain is also influenced by a patients' individual developmental, environmental, and socio-cultural background. If pain is not adequately managed acutely there is good evidence suggesting that untreated pain may have long-term negative effects on pain sensitivity, immune functioning, neurophysiology, attitudes, and health care behavior. It is therefore essential that health care professionals looking after children of all ages are trained to recognize and treat pain whether it is acute or chronic (27).

Inadequacies in the pain management process may not be tied to myth and bias originating from general attitudes and beliefs, but reflect inadequate pain knowledge (26).

Survey revealed in Ethiopia in 2007 that 60-80% of patients presenting with complaint of pain and proper pain assessment is generally considered a prerequisite for proper pain treatment.

Study reveals, nurses have a central role in assessing patients' pain and providing pain treatment options; therefore, they are in a position where they can decrease the number of children suffering from pain and the under-treatment of pain (1).

According (2004) study, nurses are more worried about addictive behavior when families children request pain medication than adequately treating severe pain. Also found that nurses spend little time assessing the effect of pain on the patient's daily life and do not understand the importance of pain management. A different study looked at pediatric nurse's pain practices. They found that some obstacles to adequate pain management included knowledge deficits about pain management 83% of the time, attitudes about pain treatment 77% and skills regarding pain management 35% of the time (7).

Another study conducted by (2000) assessed pediatric nurses' knowledge and attitudes of pain management. They found that a lack of pain management knowledge lead to inadequate management and treatment of pain. Some of these deficits included problems in assessment, pharmacological management with opioids, and knowledge of how to use non pharmacological pain interventions (25).

A pain knowledge survey of 20 true/false statements was used to measure the knowledge base of two groups of nurses. One hundred questionnaires were distributed 86 nurses returned the questionnaire giving a response rate of 86%. Following selection of the sample, 72 nurses participated in the study: 35 hospice/oncology nurses (specialist) and 37 district nurses (general). Finding showed that the specialist nurses had a more comprehensive knowledge base than the general nurses; however, their knowledge scores did not appear to be related to their experience in terms of years within the nursing profession (21).

The assessment of the child's pain management should be appropriate for the child's age and development. It includes where the pain is, what it feels like, severity and things that make the pain feel better or worse. Pain can be assessed by nurses through observation of behaviors.

Face leg, activity, cry, consol ability (FLACC) Behavioral pain assessment, there are multiple pain assessment tools that the nurse choose from .For infant, toddlers, and other children who cannot accurately express their pain, the nurse can use behavioral measures. These tool record behaviors and physical responses to pain (24).

Self -report pain assessment measures can be used for older children who are able to express their pain (36).These pain assessments require children to have a certain level of linguistic and cognitive development. Younger children between three to seven years old should use scale such as faces pain rating scale. This has different faces with a series of facial expression that reflect pain (37).Children can point out the face that describes how they are feeling. Principles of pain management as nurses, is also important to remember that have an ethical obligation to appropriately assess and treat patients' pain. Useful principles of pain management can be remembered with the "ABCDE method" as follows: Ask about pain regularly, Believe the patient's and/or family's reports of pain, Choose appropriate pain approaches and treatment options, Deliver interventions in a coordinated and timely fashion and Empower patients and their families (32).

The nurse is knowledgeable about the pharmacological interventions of opioid, non-opioid, and adjuvant drug therapies(including dosages, side effects, drug interactions, etc.) which are most effective for the most likely source of an individual child's pain. Opioids such as morphine and codeine may be administered oral, subcutaneous, intramuscular, and intravenous routes. Rectal preparations of some opioids are also available. Non opioid pain management analgesics are paracetamol, and non-steroidal anti-inflammatory drugs (NSAIDs) can be useful alone for mild to moderate pain. Ibuprofen is frequently chosen for mild to moderate pain because it is available in a liquid form allowed for easy administration to younger children (33).

Use of non pharmacologic methods of pain control with or without analgesics .One or more of this method may provide adequate pain relief when the child has low level of pain. Distraction, cuddling ,engaging in play children ,school age (3-6 years) ,talking about pleasant experience (38). Research shows up 81% of nurses working in medical and 76% in surgical ward on hospitalized children reports moderate to severe levels of pain, and that nurses administer only 23% to 43% of analgesics ordered(34).Research reveals81% inadequate pain management has been shown to affect patient outcomes by potentially increasing hospital length of stay and delaying recovery; thus, the management of pain has major implications for nursing. A nurse's knowledge and attitude can affect ability to adequately provide pediatric pain management (39).

In the Cross-sectional survey done by Senthel P Kumer (2012) in a multispecialty hospital. The study used to assess the knowledge about palliative care amongst nursing professionals utilized a self-report questionnaire- of 363 nurses on which had 20 items statements about palliative care philosophy, pain, dyspnea, psychiatric problems and gastro-intestinal problems. The finding revels knowledge of philosophy of palliative care 36.6% ,pain management 34.9%, Dyspnea in relation to oxygen saturation or use of morphine to relieve dyspnea 28.3% ,psychiatric problem and ,45% and gastrointestinal problem 34 .0%. Overall level of knowledge about palliative care was poor, and nurses had a greater knowledge about psychiatric problems and philosophy than the other aspects indicated in palliative care knowledge test (33)

Insufficient knowledge of palliative care among nurses is well documented and is considered one of the main obstacles to providing high-quality palliative care services. The study aims to evaluate Jordanian registered nurses' knowledge about palliative care. The sample consisted of 190 registered nurses working in 5 Jordanian government hospitals. Most participants were male (54%) and younger than 30 years (59%). They were working in surgical (32%), medical

(28%), and critical care (22%) units. The total mean score of palliative knowledge was low at 8.3 (SD, 2.8), ranging from 0 to 15 or (58%). The findings of the study revealed that nurses have insufficient knowledge about the essence, philosophy, and principles of palliative care. This study shows that nurses have insufficient knowledge and misconceptions about palliative care. Hence, basic education is needed for all nurses working in government and nongovernmental hospitals. This education needs to be comprehensive to cover the basic principles of palliative care and symptom management. In addition, it should address the misconceptions identified in this study (34).

In survey conducted on Knowledge and practice, care of dying children on 228 pediatrics nurses working in different hospitals, 91.9% reported that they learn by trial and error practice, 85.4% reports they learn from friends in clinical practice and 64.5 % respondent that they learned from role models during training respectively .Only 10% reported formal course in pediatrics terminal care in school (35).

In March 2012, a self-constructed questionnaire was distributed to 115 nurses at the Qatar National Center for Cancer Care and Research. A total of 115 nurses responded to the questionnaire. The majority (87.8%) were female. Although 60% had more than 10 years of work experience, only 31% had received formal training in palliative care, with only 61% having completed postgraduate training. The majority (63%) of responders attributed this issue to unavailability of palliative care courses rather than lack of time, interest, or financial issues. Currently, only 16.7% did not express interest in the field, with 56% showing some kind of interest. In terms of knowledge, 54% of the responders were familiar with the World Health Organization ladder for pain relief. Only 43.6% know about Palliative Performance Scale, and half of the nurses know the Edmonton Symptom Assessment System. Overall, 56% of the nurses indicated a need for training in more than 1 aspect. These aspects included training in care of the dying patients (14.6%), communication strategies (22%), caregiver

support (10.6%), psychosocial care (15%), pain management (10.2%), other symptom management (13%), and other ethical/spiritual issues (14.2%). There is a clear deficiency in formal palliative care education among the nurses at the National Center for Cancer Care and Research, in Qatar. This is reflected by their lack of experience and exposure to palliative care and their nursing care knowledge in the field. Formal training courses in palliative care nursing are required (36)

In a continent where access to health care is often limited, and palliative care services for children are few, the most effective way to reach children is to integrate children's palliative care into existing services for children, hospitals, clinics and community organizations, and to build competence through integrating children's palliative care training into the undergraduate (professional nurses as field of specialty) and post-graduate courses of all health care professionals (4). Family-centered care is a core value in pediatric palliative care. When chronic or critical illness occurs in a child, the family is intimately affected and challenged. When such an illness is life-threatening or life-limiting, the family's core values, relationships, and emotions are exposed and stretched to their limits. One of the primary purposes of a family is to raise healthy children, protecting them from danger and discomfort. When a family's ability to fulfill this purpose is eroded by some catastrophic event or illness, their sense of control and justice can be deeply disrupted. In the study done by oncology professionals maintain psychology and emotion of the family is primary concern of health care providers 60%of nurses are involved in caring family in addition to 37%of psychologists70% of spiritual worker . Caring for infants, children, and adolescents during critical illness and up to the end of their life is one of the most difficult aspects of pediatric practice. One fundamental aspect of this care is working with young patients, their families, and the healthcare team to make difficult decisions. These include decisions about forgoing potentially restorative or life-sustaining treatments, implementing treatments aimed at

relieving symptoms, and providing for the patients' and families' needs during the last part of their lives – be that hours, days, or months(40). A cross-sectional comparative study examined attitudes toward informed consent among nurses in the Indian State of Kashmir and Malaysia. Among 48 nurses in Kashmir, 42% reported that they disclose bad news directly to patients, and 35% said that they would ignore the family's request to withhold such information. This study points out that the fear of causing distress, depression, and suicidal thoughts in patients are the main reasons for withholding bad news about serious illness (41). Hence this study is important to lay information and investigate lack of knowledge and practice outcome of pediatric palliative care. It also identifies nurse's knowledge, background and perception impacting delivery of pediatric palliative care.

CONCEPTUAL FRAME WORK

This conceptual frame work developed is from different literatures, guide lines. It explains how individual personal information, education and experience affect nurse’s knowledge and practice towards pediatrics palliative care.

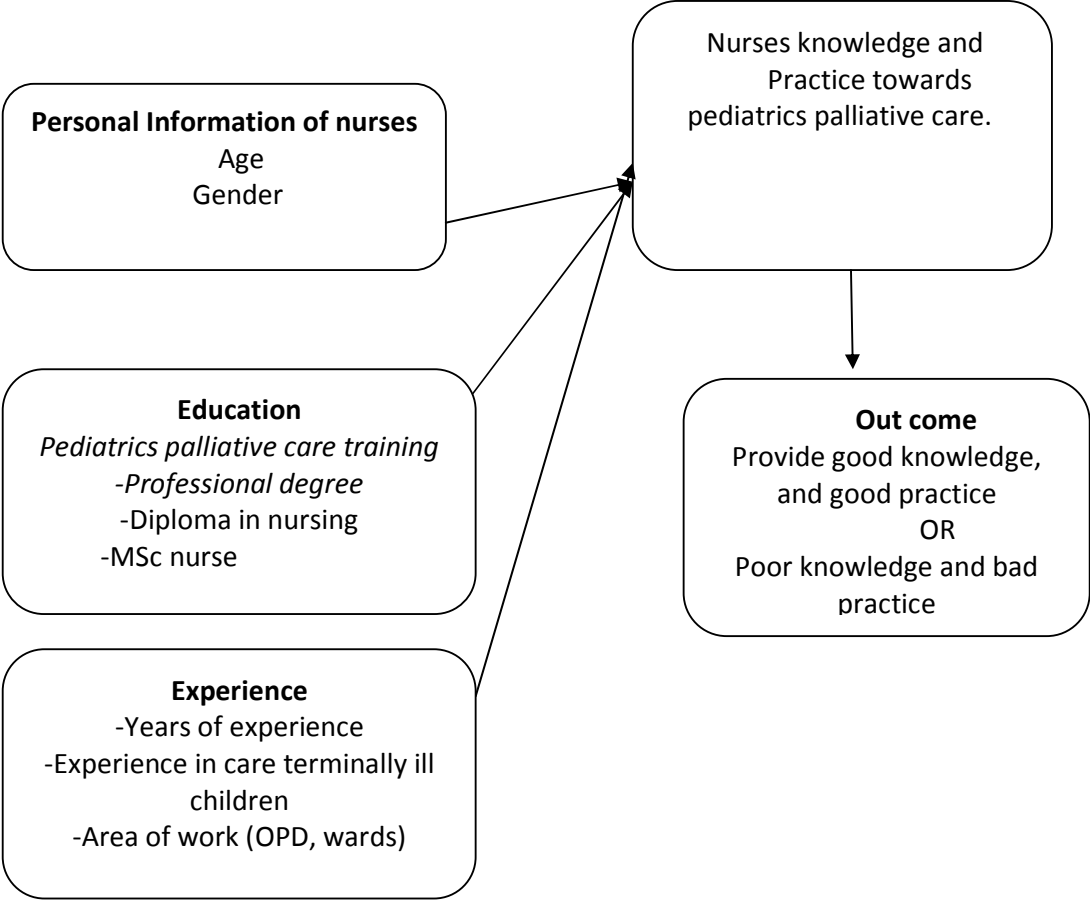


Figure I: conceptual frame work

Adopted from previously done research by Hiwot kassa (11)

CHAPTER THREE

OBJECTIVES

3.1 General Objectives:

Assess of nurses knowledge practice and associated factors towards pediatrics palliative care on nurses working at selected hospitals in Addis Ababa, Ethiopia

3.2 Specific Objective.

1. Assess knowledge of nurses towards pediatric palliative care at selected hospitals of Addis Ababa.
2. Assess practice of nurses towards pediatric palliative care at selected hospital of Addis Ababa.
3. Determine associated factor between socio demographic (age, gender, education, experiences etc...) of nurses and their knowledge and practice of palliative care.

CHAPTER FOUR

Methods and Materials

4.1. Study area

Addis Ababa is the capital city of the country, with a population of 3,384,569. Out of these 1,305,387 are men and 1,434,387 are women. It is located about 2,500 meters above sea level. Administratively, the city is divided into 10 sub-cities which are in turn divided into 99 kebeles. The health institution in the city comprises of 47 hospitals (13 governmental owned, and 34 private) 36 health centers (33 governmental and 3 nongovernmental organizations (NGOs), and 7 governmental clinics. More than 700 private and 31 NGOs clinics provide general health service in the city (unpublished, Addis Ababa city administration health bureau)

The study areas namely Black Lion (Tikur Anbessa) specialized referral, St. Paul Referral Hospital, Empress Zewditu hospital, Betel Teaching Hospital, Yekatite 12th hospital, A.L.E.R.T, and Biruk hospital. These hospitals were selected because they admit children of different ages for care and treatment.

Black Lion Hospital is established by the year 1973 G.C for the memorial of prince Mekonnen, Duke of Harar who is the son of His Imperial Majesty Haile Selassie 1st. Situated in front of the main post office and is near to National Museum, (29). It is highly accessible for transportation from any directions of the city. This Hospital serves as tertiary referral, teaching hospital of different institutions, colleges, and universities. Because of increased number of qualified, and specialized health care providers, advanced diagnostic and medical equipment Radiotherapy services, Diabetic services center, children's cardiac center and the newly opened Emergency Department and increased admission rate makes the hospital unique (28).

The second study area is Saint Paul Referral Hospital. Emperor Haile Selassie^{1st} was the founder of this hospital by the year 1973 G.C. At that, time it aimed to support poor citizens who could not afford to pay hospital fee (29). It is situated on west of Addis Ababa near to Paster Institute of Research Laboratory .It is tertiary referral hospital. In addition to routine hospital service, diagnoses and treats drug addicted patients second to Emanuel Psychiatric hospital. It services as teaching hospitals of different institution colleges and universities. Recently the hospital serves the population of Addis Ababa and accepts referral slips from different region of the country. Currently new peditrics units opened to give services.

4.2 Study period

The study was conducted in Addis Ababa town from November 25, 2013 to June 9, 2014

4.3 Study Design Institution based cross sectional study design was used.

4.4 Source population:

All nurses working in peditrics hospitals ward, peditrics emergency outpatient departments.

4.5 Study population

All nurses working in peditrics wards, outpatient, and peditrics emergency department in selected governmental and nongovernmental Hospitals.

4.6 Eligibility

4.6.1 Exclusion criteria:

Nurses not willing to participate in the study. Nurses working in central sterilization supply department (CSSD) operation room, medical, surgical obstetrics and gynecology wards adult medical and surgical outpatient department. Other professional were excluded.

4.6.2 Inclusive criteria: nurses working in peditrics, surgical, medical neonatolotolgy ward and peditrics emergency, outpatient department intensive care unit at selected hospitals irrespective of duration of work were included.

4.7 Sample size Determination and sampling procedure

4.7.1 Sample size

The sample size was determined by using formula for estimating a single population proportion.

Since there is no study done in this topic the sample size for this cross sectional study was calculated by assuming prevalence to be 50%

$$n = \frac{(z^{\alpha}/2)^2 p(1-p)}{d^2}$$

Where n= estimated sample size

P=prevalence

d=marginal error

$$n = \frac{(1.96)^2 \times 0.5(1-0.5)}{(0.05)^2}$$

$$= \frac{3.84 \times 0.25}{0.0025} = 384$$

Since the study population is less than 10,000 finite population correction formulas was applied

$$n_f = 1 + \left[\frac{n}{N} \right]$$

Where n_f =desired sample size

n= the calculated sample size

N= total population

$$n_f = \frac{384}{1 + (384/240)}$$

$$= \frac{384}{1 + 1.6}$$

$$N_f = 240$$

Adding 5% non responsive rate, the total sample size required for this study appears to be 252 nurses.

4.7.2 Sampling techniques

Majority of those selected hospitals give services for more than three decade. Nurses working in this hospital give acute as well chronic care to children of different age group. Caring for

infants, children, and adolescents during critical illness and up to the end of their life is one of the most difficult aspects of pediatric practice. Knowledge of palliative care is essential for nurses, especially in pediatrics, where palliative care is less common than with adults. However, not know which hospital or professionals might be providing pediatric palliative care, particularly in neither Addis Ababa town; nor do FMOH, Addis Ababa Health Bureau knows what the educational needs of those professionals might be. In the absence of evidence, those responsible for the development of pediatric palliative care services, curricula, courses, and learning has to develop awareness from this research. This is why need to conduct research in those selected hospitals.

There are two non-governmental hospitals namely Betel Teaching Hospital, and Biruk Hospital. Five governmental hospitals namely, Black Lion Specialized Referral Hospital, St Paul Referral Hospital, Yekatit 12 Hospital, ALERT and Zewditu Memorial Hospitals. List of nurses working in the identified hospital's pediatric ward was taken from administration office. After checking for the number of nurses, all available 240 nurses was taken to the study by adding 5% non response rate total of 252 nurses. The selection 252 nurses were performed by the following schematic presentation.

4.7.3. Proportional allocation

Based on proportionate to sample size allocation this 252 sample size distributed in hospitals.

$$n_j = \frac{n}{N} N_j$$

n_j is a sample size of the j^{th} proportionate allocation

$$n_j = \frac{n}{N} N_j$$

n_j is the sample size of the j^{th} hospital

N_j is population size of the j^{th} hospital

$n = n_1 + n_2 + n_3 + n_4 + n_5 + n_6 + n_7$ is the total sample size

$N = N_1 + N_2 + N_3 + N_4 + N_5 + N_6 + N_7$ is total population size of hospitals

N_j is population size of the j^{th} hospital

Proportion allocation

Total population = 271= n = 252

1. Black lion Hospital $\frac{120 \times 252}{271} = 111$

271

2. .Zewditu Hospital $\frac{40 \times 252}{271} = 37$

271

3. Yekatite 12th hospital $\frac{35 \times 252}{271} = 32$

271

4. St Paul hospital $\frac{27 \times 252}{271} = 25$

271

5. ALERT hospital $\frac{14 \times 252}{271} = 12$

271

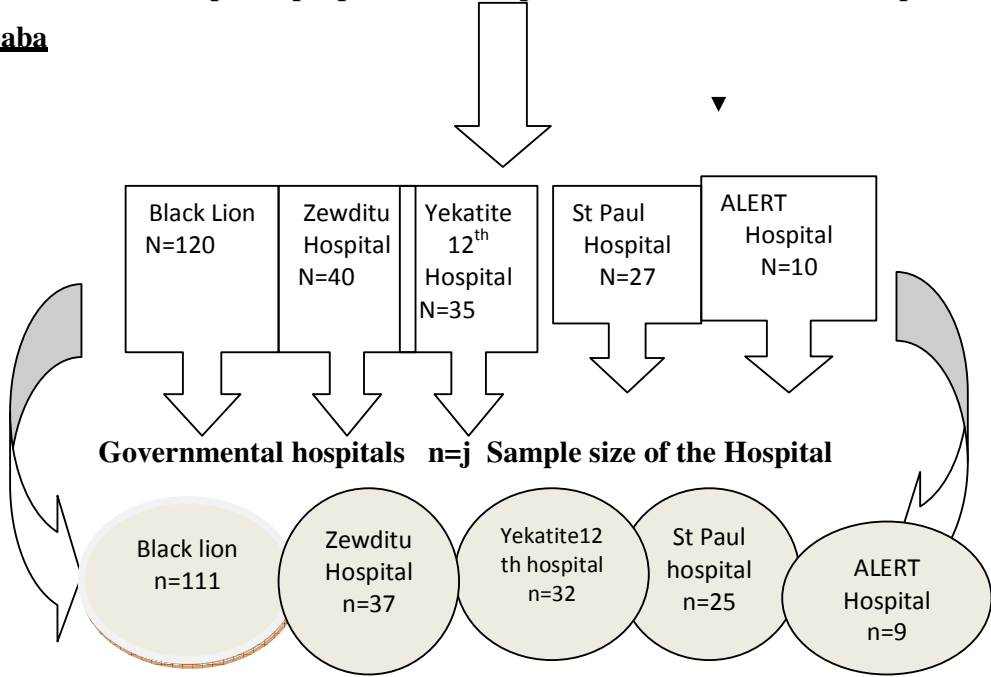
6. Biruk Hospital $\frac{16 \times 252}{271} = 15$

271

7. Betel Teaching Hospital $\frac{26 \times 252}{271} = 24$

271

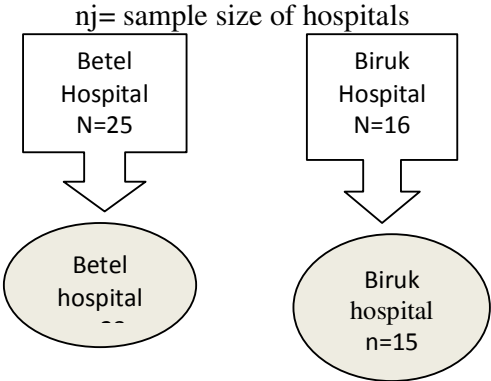
Governmental Hospital proportional sample allocation in selected hospital of Addis Ababa



Total Governmental Hospitals sample size

$$(111) \text{ Black lion} + (37) \text{ Zewditu hospital} + (32) \text{ Yekatite hospital} + (25) \text{ st paul} + (9) \text{ ALERT} = 214$$

Nongovernmental hospital proportional Sample allocation in selected hospital of Addis Ababa.



Total Non –Governmental Hospital (23) Betel hospital+ (15) Biruk hospital = 38

$$(214) \text{ Governmental hospital} + (38) \text{ Non Governmental hospital} = \text{Total sample size 252 was used for this study.}$$

Figure: II Schematic representation of sample procedure

4.8 VARIABLE

4.8.1 Independent variables

Age

Gender

Professional degree

Year of experience

Level of education

Year of service

Experience in care of terminally ill child

Training on palliative care

4.8.2 Dependent variables

Knowledge on palliative care

Practice on palliative care

4.9 Methods of data collection

4.9.1 Quantitative Data

Data was collected with structured questionnaires. This consists of socio demographic variables, educational level, service year, training on palliative care, experiences in caring terminally ill child.

4.9.2 Qualitative data

The qualitative data collected by prepared semi structured questionnaires. Nurses were selected from three hospitals (Balck Lion Referral, Yekatite 12 and Betel Teaching) and organized in a group from each hospital for focus group discussion. Total of three groups, one group contains 6-8 members. Group facilitator who has ability to guide for each group was assigned. In depth interview was conducted. The interview, from tape record was transcribed by the principal investigator. Later the transcribed information arranged under each theme and narration took place to use for result.

4.10. Pre testing the questionnaire

Pre test was conducted on 10% of nurses in Ras Desta Hospital estimated to the sample size. The purpose of pre tests was to check for clarity of language, acceptability, validity and completeness of the questionnaires. For any missing, options and based on the feedback finally necessary correction and modification was made.

4.10.1 Data Collection Instrument and Technique

A knowledge questionnaire was adopted from palliative Care Quiz for Nursing (PCQN) and previous research according to Ethiopian context (11). The instrument has three section One- socio demographic variables.

Section two: knowledge question from Palliative Care Quiz for nursing (PCQN) arranged as Yes ,No, and Don't know questions PCQN in previous research with an internal

consistency of 0.78 which indicate as high internal consistency with possible score range from 1-17 the highest score (> 75%) indicates good knowledge (11,34).

Section three contains 11 practical question developed on common pain assessment guide and pain rating scales practical questionnaires as well partially from (APCA/POS) African palliative care Association/ palliative outcome scale for Africa (4).

4.11 Data Collection.

Data was collected face to face by self administered questionnaires. The questionnaire was distributed for the selected hospital pediatric ward nurses. Six supervisors who have Master in other health related field and knowledge of supervision were recruited from each governmental and nongovernmental hospital. The responsibilities of the supervisors were to follow whether the questionnaire was correctly completed or not and, report only problem encountered immediately to the principal investigator. One day training was given on the data collection procedures, techniques of forwarding the questions to get the necessary information.

4.11.1 Data processing

The data was checked for its completeness and entered in to SPSS version 21.

4.11.2 Quantitative Data

Variable regarding assessment knowledge on the palliative care of nurses was classified to a particular item, and practical knowledge pain assessment and management was merged to a particular item. Data was checked for completeness and analyzed using SPSS version 21.

The analyzed data was described using simple description statistics, table percentages, and frequencies, graphs and narrative used depending up on the nature of data. Odds Ratio was computed to see their association.

4.11.3 Qualitative Data

Qualitative part of data was presented in narrative form under each theme. The transcribed data from tape-record organized under each theme step by step by taking note according its similarity and differences to question on the guide line. Later qualitative result presented in narrative way.

4.11.4 Data quality control

Based on the objectives of the study the questionnaire was attempt to cover all the necessary information .One day training was conducted for the data collectors during this time the principal investigator brief them about the questioner, the objective of the study, how to approach the participants, how to administer and collect the questioner from the study population on time. A pre test was done on nurses working in Ras Desta Damitew Hospital this was not included in actual data collection. Then the questioner was revised before the actual data collection. Confidentiality of the study participants were kept before during distribution and data collection time. Take it to ethical clearance part Coding and entry were checked throughout the process.

4.12 Statistical Analysis

The data was entered in to EPI-INFO 3.5.4 version and the exported to SPSS version 21 software statistical packages The analyzed data was described using simple description statistics, table percentages, and frequencies, graphs and narrative used depending up on the nature of data. Odds ratio and logistic regression was computed in order to assess statistical association and to see the level of significance.

4.13 Ethical consideration

Ethical clearance was obtained from the AAU Institutional review board (IRB). Permission was obtained from Addis Ababa University School of Allied Health Science Department of nursing and midwifery. And an official letter was written to the selected hospitals and to get their permission and cooperation for the study Again permission was obtained from medical directors,' matrons and head nurses of each hospital pediatrics wards. Verbal consent will be

obtained from each participant and participant's anonymity and confidentiality was kept. Nurses are autonomous whether to participate or not to participate in the study.

4.14 OPERATIONAL DEFINITIONS

Good knowledge = $\geq 75\%$ of total score of the Palliative Care Quiz for Nursing (PCQN) scale (35)

Poor knowledge = $< 75\%$ of total score of the PCQN scale

Knowledge Aspect of Practice = the nurse must have a knowledge on palliative care regarding application of Practice.

Good knowledge aspect of practice = $\geq 75\%$ of the total knowledge aspect of practice questions.

Poor knowledge = $< 75\%$ of total knowledge aspect of practice questions

4.15 Dissemination of information

The result will be submitted to Addis Ababa University, School of Allied Health Sciences Department of Nursing and Midwifery and Addis Ababa Health Bureau, Ministry of Health also for those hospitals that participated in the study to utilize the information for further development of strategic and educational plan promotion of nurse's knowledge and practice towards pediatric palliative care. The result of this study will be presented on conferences, workshops. Further it will also send to Journal for publication.

CHAPTER V RESULT

5.1 SOCIO –DEMOGRAPHIC CHARACTERISTICS OF NURSES

This study involves nurses working in governmental and nongovernmental hospital. The total number of participants was 252 and the response rate was 249 (98.8%). Three was excluded from analysis due to incomplete data. The data were collected from Black Lion Specialized Referral Hospital 111 (45.0 %), Zewditu Hospital 37 (14.9 %), Yekatite 12 Hospital 31(12.4%), St, Paul Referral Hospital 24 (9.6%), Betel Teaching Hospital 21(8.4%), Biruk Hospital 12(4, 8%), ALERT 12 (4.8%). Among 249 nurses who completed the questionnaires, majority of participants 191 (76.7%) were female and 58 (23.3%) were male and the mean age of respondents was 31.13 ± 8.42 SD (ranged from 21 to 60). The respondents were working in the neonatal ward 51 (20.5%), Pediatrics emergency unit 49 (19.7%) Surgical ward 41 (16.5%) Outpatient department 36 (14.5%), Medical ward 32 (12.9%), Oncology 28 (11.2 %), pediatric intensive unit 12(4.8%). Of all respondents 194 (77.9%), 53(21.3%), and 2(0.8%), had degree, diploma and master respectively. More respondents 113(45.4 %) had less than 5 years of experience 90(36.1%), 26 (10.4%), 20 (8.0%) had 5 to 10 years, 11 to 15 and more than 16 years of experience, respectively. Majority of respondents 202(81.1%), had daily experiences of caring terminally ill children 33(13.3%), 6 (2.4%) 4(1.6%), 4(1.6%) were caring terminally ill children once per week, once per month, few times per year and had never experience caring terminally ill children, respectively. From study participants the majority 189 (75.9%) had no training on pediatrics palliative care, 60 (24.1%) had training among of those 53 (21.3%), 1 (0.4%) were trained for 1 to weeks and one month respectively. (Table 1)

TABEL 1: Socio Demographic Characteristics Of Nurses At Selected Hospitals In Addis Ababa . (N=252)

Characteristics	Frequency N (250)	Percentage %(100)
Institutions		
Black lion	112	45
Zewditu Hospital	37	14.9
Yekatit12 Hospital	31	12.4
St, Paul Hospital	24	9.6
Betel teaching	21	8.4
Biruk Hospital	12	4.8
ALERT hospital	12	4.8
AGE		
21-30 years	165	66.1
31-40 years	45	18.0
41-50 years	34	13.6
>50years	5	2
Gender		
Female	191	76.7
Male	58	23.3
Level of Education		
Diploma	53	21.3
Degree Bsc	194	77.9
Msc	2	0.8
Year of experience working in pediatric ward		
Less than 5 years	113	45.4
5-10 years	90	36.1
11-15years	26	10.4
More than 16 years	20	8.0
Current pediatric ward assignment area		
Neonatology ward	51	20.5
Pediatric emergency unit	49	19.7
Surgical ward	41	16.5
Pediatric out patient	36	14.5
Medical ward	32	12.9
Oncology	28	11.2
PICU	12	4.8
Experience in caring terminally ill child		
Daily	202	81.1
Once per week	33	13.3
Once per month	6	2.4
Few times per year	4	1.6
Never	4	1.6
Any training		
Yes	60	24.1
NO	189	75.9
How long you had		
1-2 weeks	53	21.3
1month	1	0.4
Never	193	77.5

5.2 Nurses Knowledge towards Pediatrics palliative Care

One hundred seventy one (68.7%) of the respondents knew the definition of palliative care and similar number of nurses responded that manifestation of chronic pain are different from those of acute pain 193(77.5 %) agreed that the extent of the disease determines the method of pain treatment 187 (75.1%) responded that drug addiction is a major problem when morphine is used on a long term.121(48.6%) were agreed that adjuvant therapies are important in managing pain. Nearly more than half 144 (57.8) of the respondent agreed accumulation of loses render burn out those work in palliative care. 217 (87 .1%) of nurses reopened that an increase in vital sign help as pain assessment tool,110 (44.2%), 153(61.4%) and 129 (51.8%) nurses were agreed that families of terminally ill child have hope against all odds, undeveloped nervous system decrease pain sensitivity in children under two years of age, and children distracted from pain usually do not have severe pain, respectively. Out of the total study participants only 37(14.8%) had good knowledge toward pediatric palliative care (Table 2).

Table 2 Distribution of nurse's knowledge toward pediatrics palliative care in selecte Hospitals in Addis Ababa, Ethiopia. March – June2014

No	Characteristics	Yes N (%)	No N (%)	Don't Know N (%)
1.	Do you know the definition palliative care?	171(68.7)	66 (26.5)	12 (4.8)
2.	Palliative care is only appropriate in situations A downhill trajectory or deterioration conditions	90(36.1)	124(49.8)	35(14.1)
3.	The extent of the disease determines the Method of pain treatment	193(77.5)	48(19.7)	7(2.8)
4.	Adjuvant therapies are important in managing pain	121(48.6)	70 (28.1)	58(23.3)
5.	Drug addiction is a major problem when morphine is used on a long- term basis for the management of pain	187(75.1)	46(18.5)	16(6.4)
6.	The provision of palliative care require emotional detachment	74(29.7)	121(48.6)	5421.7
7.	During terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea	106(42.6)	107(43.0)	36(14.5)
8.	The philosophy of palliative care is compatible With that of aggressive treatment	59(23.7)	106(42.6)	84(33.7)
9.	The use of placebo is appropriate in the treatment of some type of pain	157(63.7)	49(19.7)	43(17.3)
10.	Meperidine (Demerol)is not an effective analgesics for the control of chronic pain	28(11.2)	85(34.1)	43(17.3)
11.	The accumulation of loses renders burn out inevitable for those who work in palliative care.	144(57.8)	51(20.5)	54(21.7)
12.	Manifestation of chronic pain are different from those of acute pain .	171(68.7)	68(27.3)	10(4.0)
13.	Terminally ill children families have the right to choose “ Do not resuscitate (DNR)	65(26.1)	134(53.8)	49(19.7)
14.	Families of terminally ill child should have hope against all odds	110(44.2)	89(35.7)	50(20.1)
15.	Increase in Vital sign help as pain assessment tool	217(87.1)	30(12.0)	2(0.8)
16.	Because their nervous system is underdeveloped, children under two years of age have decreased pain sensitivity and limited memory of painful experiences.	153(61.4)	67(26.9)	29(11.6)
17.	Children who can be distracted from pain usually do not have severe pain. Patients may sleep in spite of severe pain.	129(51.8)	94(37.8)	26(10.4)

5.3 Practice of nurses towards pediatric palliative care.

More than half 243(97.5 %) of the respondent had poor knowledge aspect of practice towards pediatric palliative care and 190(76.3%) initiate pediatric palliative care discussion to the family during diagnosis. 148(59.4%), inform to the family their child's terminal stage illness. Concerning decision making 156(62.7%), of the respondent were involve the family with regard addressing psychological issue of the child during child care 117(47.0%), concerning the child 's family ,86(34.5%), emotional support 64(25.7%),play with child according to the age 23(9.2%), Hide the truth about progress of the disease . More than half of the respondent perceives the families of terminally ill child or the child as his /her age when asks question for concern patient right 171(68.7%), attention seeking behavior 48(19.3%), treat 33(13.3%), doubting profession 16(6.4%) respectively. Regarding factors to consider when dealing with family of terminally ill child, Psychological condition 113(45.4%), Medical situation 108(43.4%), spiritual /religious 73 (30.1%) and cultural 38(15.3%). Concerning information communication to the family of terminally ill child depend on family ability to assimilate 121(48.6%), Involvement of the family in decision making 106 (42.6%), willingness to disclose information 38(15.3).The commonly used medication for severe pain were Paracetamol suppository/Ibuprofen 217(87.1%),followed byMorphine33(13.3%),Codeine 14(56%).Concerning Pain assessment on children, more than half of the respondents agreed observation 129 (51.8%), using tools of assessment 70 (8.1%), grade pain with face 62(24.9%), and intensity 27(0.8%) respectively(Table 3).

TABLE 3 .Practice of nurses towards palliative care at selected hospital in Addis Ababa, March -June, 2014

NO	Characteristics	Multiple Response	YES N(%)	NO N(%)
1.	Initiate palliative care discussion	During Diagnosis	190(76.)	59(23.7)
		When the disease progress	81(32.5)	168(67.5)
		At the end of life	52(20.9)	197(79.1)
2	Do you inform to the family their child's is in terminal stage	Yes	148(59.4)	101(40.6)
		No	38(15.3)	211(84.7)
		Depending on family 's wish	45(18.1)	203(81.5)
		Inapplicable	27(10.8)	222(89.2)
3.	What are the factors you consider when dealing with the family terminally ill child	Spiritual /religious	75(30.1)	174(69.9)
		Medical situation	108(43.4)	141(56.6)
		Cultural	38 (15.3)	211(84.7)
		Psychological condition	113(45.4)	135(54.2)
4.	How would address spiritual issues and your concern to the child's family	Connect with spiritual counselor or pastor	93(37.3)	156(62.7)
		Listen with empathy	69(27.7)	180(72.3)
		Impose your own view	41(16.5)	208(83.5)
		Understand child's family reaction to the loses of their child's life	78(31.3)	169(67.9)
5.	Culture assessment during child care should include	Truth telling and decision –making with	125(50.2)	124(49.8)
		Preferences regarding disclosure of information	46(18.5)	203(81.5)
		Dietary preference	19 (7.6)	230(92.4)
		Language, family communication	67(26.9)	182(73.1)
		Perspective of death ,suffering and grieving	29(11.6)	220(88.4)
6.	How do you address psychological issues of the child during child care	Emotional support	86(34.5)	163(65.5)
		Counseling the child's family	117(47.0)	132(53.0)
		Play with child according to age	64 (25.7)	185(74.3)
		Hide the truth about progress of disease	23(9.2)	225(90.4)
7.	In your current practice whom do you involve in the decision - making process related child's condition	Child according to age	57(22.9)	192(77.1)
		Family	156(62.7)	93(37.3)
		My own	37(14.9)	211(84.7)
		Other health professionals	31(12.4)	218(87.6)
8.	Do you perceive the families of terminally ill child or the child as his age when they ask question or concern	Patients right	171(68.7)	78(31.3)
		Threat	33(13.3)	216(86.7)
		Doubting your profession	16(6.4)	233(93.6)
		Attention seeking behavior of child's family	48(19.3)	197(79.1)
9.	Information communication to the family of terminally ill child depends on	Family ability to assimilate	121(48.6)	128(51.4)
		Their involvement of decision making	106(42.6)	142(57.0)
		Your willingness to disclose information	38(15.3)	210(84.3)
10.	Type pain medication /analgesics commonly used in your practice for pain	Paracetamol suppository/syrup /Ibuprofen	217(87.1)	32(12.9)
		Codeine	14(56.0)	234(94.0)
		Morphine	33(13.3)	215(86.3)
11.	How do you assess children pain	Using tools for assessment	70(28.1)	179(71.9)
		Observation	129(51.8)	120(48.2)
		Grade the pain with the face	62(24.9)	184(73.9)
		Intensity	27(10.8)	222(89.2)

5.2 ASSOCIATION BETWEEN SOCIO DEMOGRAPHIC VARIABLES AND NURSES KNOWLEDGE TOWARDS PALLIATIVE CARE

Knowledge increases when the level of education increases i.e. Respondents with BSc degree and MSc level of education, are more knowledgeable than diploma nursing(diploma nurses vs. BSc nurse AOR=1.62,95%CI=1.38,3.35 and diploma nurse vs. MSC nurse AOR=1.45,95%CI=1.22,3.77). On the other hand those who do not take training were less knowledgeable than who took training (AOR=1.3, 95%CI=1.01, 3.62) (Table 4).

Table .4 Association Between Socio Demographic Variables And Nurses Knowledge Towards Pediatrics Palliative Care At selected hospitals in Addis Ababa.

Characteristic		knowledge		COR (95% CI)	P - value	AOR (95% CI)	p- value
		Good n (%)	Poor n (%)				
	21-30years (Ref)	28 (75.7)	137(64.6)				
	31-40 years	9(24.30)	36(17.0)	0.81(0.35,1.88)	0.63	0.91(0.35,1.48)	0.76
	41-50 years	0 (0.0)	34(16.0)	0.27(0.041,1.12)	0.39	0.37(0.14,1.22)	0.43
	Above 51 years	0 (0.0)	5(2.4)	0.57(0.014,1,23)	0.59	0.41(0.03,1,13)	0.29
Gender	Female (Ref)	8(75.5)	163(76.9)				
	Male	39(24.3)	49(23.1)	0.93(0.41,2.11)	0.87	0.84(0.31,3.12)	0.68
Level of education	Diploma (Ref)	8(21.6)	45(21.2)				
	Bsc degree	29(78.4)	165 (77.8)	1.23(1.02,3.05)	0.04*	1.62(1.38,3.55)	0.02*
	Msc degree	0(0.0)	2(0.9)	1.45(1.01,3.45)	0.03*	1.45(1.22,377)	0.04*
Pediatric ward work experience	Less than years (Ref)	19(51.4)	94(44.3)				
	5-10 years	16(43.2)	74(34.9)	0.93(0.44,194)	0.85	0.83(0.53,2.04)	0.44
	11-15 years	2.(5.4)	24(11.3)	2.42(0.52,11.13)	0.25	2.42(0.42,911)	0.35
	Above 16 years	0.00	20(9.4)	1.51(0.23,2.12)	0.19	1.43(0.73,2.23)	0.20
Training on pediatric palliative care	Yes (Ref)	13(35.1)	47(22.2)				
	No	24(64.9)	165(77.8)	1.9(1.02,4.02)	0.04*	1.3(1.01,3.62)	0.04*

*(Statistically significant at p-value 0.05)

5.5 ASSOCIATION BETWEEN SOCIO DEMOGRAPHIC VARIABLES AND NURSES PRACTICE TOWARDS PALLIATIVE CARE

Female respondents were good at practice than male respondents (AOR=0.058; 95%CI=0.005, 0.67).The higher the year of working experience the less practice reported (AOR=0.016; 95%CI=0.000, 0.66). Respondents with age from age 41-50 had less practice aspect of when compared to other age groups (COR=0.06 95%CI=0.006,0) (Table 5).

TABLE 5: The association of socio- demographic characteristic and practice of nurses towards pediatric palliative care at selected hospital in Addis Ababa, Ethiopia March –June 2014

Characteristic	Practice aspect of knowledge		COR 95% CI	P- value	AOR 95% CI	p- value
	Good N (%)	Poor N (%)				
Age	21-30years (Ref)	1(16.7)	164(67.5)			
	31-40 years	2(33.3)	43(17.7)	0.13(0.01248)	0.1	0.51(0.027, 9.76)
	41-50 years	3(50.0)	31(12.8)	0.06(0.006,6)	0.01*	0.61(0.028, 13.67)
	51-60years	0.(0.0)	5(2.1)	0.12(0.01,2.45)	0.45	0.65(0.05,8 .45)
Gender	Female (Ref)	3(50.0)	188(77.4)			
	Male	3(50.0)	55(22.6)	0.29(0.05,1.49)	0.13	0.058(0.00 5,0.67)
Level of education	Diploma in nursing (Ref)	1(16.7)	52(21.4)			
	BscDegree in nursing	5(83.3)	189(77.8)	0.24(0.03,1.12)	0.60	0.39(0.02,5. 96)
	Masters In nursing	2.(50.0)	1 (0.8)	0.35(0.08,0.19)	0.72	0.35(0.04, 4.67)
Pediatric ward work experience	Lessthan5 years (Ref)	1(16.7)	112(46.1)			
	5-10years			0.07(0.03,1.063)	0.64	0.067(0.12 ,2.06)
	11-15 years	3(50.0)	23(9,5)	0.068(0.007,0.68)	0.02*	0.03(0.002,0 .08)
	>16 years	2(35.3)	18(7.4)	0.08(0.007,0.93)	0.04*	0.016(0.000, 0.66)
Training on pediatric palliative care	Yes(Ref)	1(16,7)	59(24.3)			
	NO	5(83.3)	188(77.4)	0.62(0.07,5.44)	0.66	

(Statistically significant at p -value =0.05)

CHAPTER VI DISSCUSION

Palliative care is now recognized as a basic human rights issue and children and families have a “right to health,” or a right to receive such care. Children have the same right to palliative care as adults (14). Palliative care is defined by the World Health Organization (WHO) as “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 (4).

Estimates of the need for palliative care for children globally vary, but upwards of seven million children are in need of palliative care services today. (22). The result of nurses response, in study hospitals, as Black Lion 11(29.7%), Yekatit 12, 7(18.9), Zewditu, 7(18.9), St, Paul, 6(16.2) Biruk 4(10.8%), and Betel 2(5.4), hospital has peditrics palliative care knowledge respectively. Concerning level of education majority of respondents as 29(78.4%) bachelor holder nurses had more knowledge than , diploma nurses 8(21.6%) in peditrics palliative care knowledge .This might be due to longer period of education, in basic nursing. Nurses working in peditrics emergency unit 11(29.7%), Neonatology ward 9(24.3%), working experience in peditrics ward, for less than 5 years 19(51.4%), and had training on peditric palliative 41(68.3%), age between 21-30years 28 (75.5%), were found with good knowledge in this study.

The result of this study showed majority 82.3% of nurses had poor knowledge towards peditrics palliative care. The substantial reason for this might be only 24.1% were trained on peditrics palliative care of all. In this study training and level of education had significant association with knowledge. Bachelorette and master nurses were more knowledgeable than diploma nurses. This might be due duration and in-depth training. University admission criteria for Bachelor and Masters nursing are different than for diploma nurses. Nurses with

level of bachelor are professional and educated in institution of higher learning and function in responsible and accountable manner. Critical thinking is now being emphasized to great extent. Nurses at bachelorette level exist in response to a need of society .Master in nursing independent practice with continued emphasis on research. Nurses who had no training were more knowledgeable than those who took training (Table 3). This might be the number of nurses who had is only 24% comparatively, duration of training is short. In this study, age, gender, work experience, caring for terminally ill children were not associated with knowledge. This study result contradict the study from Ottawa 87.1 % disagreed that palliative care is only appropriate in situations a downhill trajectory or deterioration condition, where as 36.1% agreed individual receiving aggressive treatment, such as those with chronic diseases, AIDS and certain type of cancer where there is no hope for cure may receive the supportive aspect of palliative care, beginning at the time of diagnoses (35). This response might be due to unavailability of children's hospital for chronic life limiting diseases care or it may palliative care is new emerging type of care in Ethiopia. On other studies adjuvant therapies (combined analgesic) are important in managing pain; in other study response was 89.7% were as in this study 48.6% agreed. It was emphasized the importance of using adjuvant analgesics (antidepressant ,antiemetic) and non drug adjuvant measure such as patient education and relaxation in management and control of pain .The reason why the response rate is lower than other study is, most of the time nurses are not exposed to prescribe drugs or there is no separate chronic care center (26.35,38).

On knowledge question of drug addiction as major problem morphine is used on long term basis for the management of pain, 77.4% of the respondent agreed which is a contradicting response from Canada 92, 9% of the answer was no or disagree. On this point researcher reveal that ,in patients with chronic pain do not and cannot get addictive to morphine .The author reports when pain is abolished even with high doses of morphine used for several

months, the use of morphine can be stopped with no withdrawal effect(26,35,38). Research also revealed that the serious deficiencies under graduate nursing education and nursing knowledge to end of life care (11, 35).

Furthermore, the result agreed with studies conducted in (Qatar, Lebanon and Germany) level of education had relation with knowledge (3, 26, and 35). This might be palliative care was not incorporated into either diploma or degree curricula. Also this is deficient of nurses to be knowledgeable and competent in caring children with life threatening diseases. In current study from one hundred ninety eight bachelor holder nurses , 29(78.4%) responds as good on knowledge of Palliative care followed by fifty three diploma holder 8(21.6%) ,bachelor holder nurses were more knowledgeable than diploma holder nurses. This may show the outcome of education, or understanding the concept. Knowledge of palliative care is essential for nurses, especially in pediatrics, where palliative care is less common than with adults.

Regarding Knowledge aspect of practice of nurses 97.5% had poor practical knowledge of pediatrics palliative care. This study is in line with the study done in Germany 91 .9% of the study respondents do practice of palliative by trial and error (35). The reason for poor practice in this finding, majority of the respondent had poor knowledge of pediatrics palliative care this might be due to experience; most of them had less than five years work experience, since experience affect the practice. Initiate palliative care discussion, During diagnosis 86% response of nurses is in line with current study 78% of respondent discussions and decision-making during pediatric palliative care may involve, directly or indirectly, the patient's parents, siblings, entire families, and communities (22).These studies reveals significant associations of female respondents were found good with knowledge aspect practice of pediatric palliative care than male. This might be due to high concentration to practice and or their number is high than male nurses. Year of experiences is significantly associated with

knowledge aspect practice palliative care (Table 5). The higher the year of working experience the less the practice reported. May be because concept of palliative care new emerging to practice. Experienced nurse may consider themselves as having practical knowledge. Over all the more they are experienced, but the less they attend in seminars, training, attending ground round where they can update themselves. In ward where they work, no library books and journals. A range of essential knowledge that can be used to inform nursing practice, acknowledging the importance not just of scientific knowledge, but of knowledge developed through experience, personal understanding and interpretation and of moral and ethical reasoning.

Age has significant association with practice aspect of palliative care .The higher the age the less the practice of nurses. Palliative care is newly up-and-coming type of care to life threatening condition of children. In some hospitals there is separate room for chronic critical care, in some not because of this they may had less exposure.

In each care decision of discussion requires weighing and periodic re-evaluation of the potential benefits, burdens, and risks. The relative importance of these factors varies between situations and families, and may fluctuate over time as the goals of care change with disease progression (22).

Concerning this study, 59.4% of nurses inform to the family that their child's is in terminal stage. This response is less from the study done in Australia which is 79%. The reason why all nurses not inform terminal illness of the child to the family might be nurses consider that it is the responsibility of the physician or, one of the primary purposes of a family is to raise healthy children, protecting them from danger and discomfort. When a family's ability to fulfill this purpose is eroded by some catastrophic event or illness, their sense of control and justice can be deeply disrupted, frustration and anxiety may occur (38). This difference might

be because of cultural difference that in Ethiopia delivering bad news or talking about death in front of children or family is a taboo and it is also difficult.

For factors of nurse to consider when dealing with the family of terminally ill child on Psychological condition (45.4%) response is less than other studies. This study contradict from the study done in Canada where 60% of nurses participate in psychological care of the family in addition to 37% psychologists and 70% of spiritual workers (40).

The reason why nurse response is lower than previous study might be due to less exposure to critical care ward. The finding of this study reveals that 43.4% of respondents consider medical situation as next to psychological condition, spiritual /religious 30.1% and cultural situation 15.3% when treating terminally ill children.

This finding is concurrent with study from Kampala stating that the majority of nurses take medical condition into consideration when working with terminally ill children (4). This might be consideration of nurses as most families accessible to use health facilities in case if children became sick.

Regarding practice of spiritual care, 37.3% of nurses connect the family with spiritual counselor or pastoral according their child's religion, this is to make families, pay attention and getting information about their problem. More than 61% staff nurses use spiritual care for children and families, leading to the implementation of spiritual interventions and earlier referrals to pastoral care when appropriate (6). This could be what most nurses give great value and concern for religion accordingly .

More than half of respondents (50.2%) address truth telling, preference regarding disclosure of information as 18.5% dietary preference 7.6%, language, family communication as 26.9% perspective of death and suffering as 11.5% this study is congruent with study done in India. The amount of information provided at the initial consultation will depend on the parents' informational and emotional needs. Communicating a new diagnosis is not a discrete event,

but a continuous one, requiring further contact and information provided at a later time. Often the question whether it is ethical to disclose bad news directly to patients or not is grounded in cultural values. Concealment of bad news is more common in the case of a terminal disease and often justified on the grounds that truth telling condemns a patient to social death, by which is meant treating a living person as if they are already dead. (41)

47% of the nurse addresses psychological issues of the child during child care by hiding the truth progress of the disease. Concurrently, high rate of life-threatening diseases and consequently plenty of clinical bad news. Bad news in the life prospects of a patient is defined as “any news that drastically and negatively alters the patient's view of her or his future. Another study revealed that 42% of nurses said disclose patients condition and 35% ignores patient request of disclosure (41). In contrary studies in Denmark and Norway reported the majority of nurses viewed that lying to the patient or child’s family about their diagnosis is unethical and violation of principle of ethics(11). On the other hand the reason for hiding the truth as described in this study could be that nurse believed the truth will hurt the patient and child’s family to have hope ,which contradict the ethical principles truth telling and honesty. More than 68.7% of nurses perceive those families of terminally ill child or the child as his age when they ask question or concern patient right. The significance and approach used for truth-telling, is strongly tied to an individual’s or family’s religious and cultural practices and values. A child also has the right to waive the option of receiving this information, preferring instead that parents receive information on his or her behalf (26).

Concerning, medication correctly used for chronic pain management majority 87.1% nurses use paracetamol/ Ibuprofen. This might be due to shortage of opioid analgesics and or poor awareness about chronic pain management. Most of the time it is prescribed by physician, and lock kit drug. Untreated pain can have serious physiological, psychological and social consequences. It can limit the ability to sleep, perform everyday tasks and exercise. It also

reduces mobility and appetite, aggravates other health problems and makes it harder to recover from an injury or fight infection due to depressed immune system (25)

In this study 51.8 % of respondents use observation to assess children pain. This result is agreed with response of focus groups in this study. A different study looked at pediatric nurse's pain practices. They found that some obstacles to adequate pain management included knowledge deficits about pain management 83% of the time, attitudes about pain treatment 77% and skills regarding pain management 35% of the time (7). Another study conducted by (Ian Anderson 2000) assessed pediatric nurses' knowledge and attitudes of pain management. They found that a lack of pain assessment knowledge lead to inadequate management and treatment of pain. This might be that the area where the study was conducted was the responsibility of the physician to carry out pain assessment.

Policy and Practice Implications Education pediatric palliative care involves an integrated multidisciplinary collaborative teamwork of patients, their families' health professional and general public towards a continuum of care emphasizing on physical, mental, social, spiritual and emotional aspects of care for life threatening conditions. Education and training in palliative care influences not only the level care provided but also the level of team participation of the health care professional. Nurses simply do not feel comfortable or competent in providing such care there is no formal education. Lack of education is general nursing knowledge deficit. There was and is striking care lack of formal education in pediatric palliative for nurses. Palliative care education and training should be looked at as an ongoing process that begins at undergraduate level and continues through specialist training and into continuing education.

Education and training should aim at developing not just knowledge and skills but also attitudes, beliefs and values. Training needs to be competency-based to ensure that the knowledge is applied at the various levels of service delivery, from primary to specialist

services. This is critical for ensuring appropriate knowledge, skills and attitudes for all service providers, including care providers, patients, families and the general public. In this study, nurses' knowledge and practice of palliative care found poor. Insufficient knowledge of pediatric palliative care among nurses well documented. Addis Ababa Health Bureau and Federal Ministry of Health had high responsibility palliative care services for children. The most effective way to reach children is to integrate pediatric palliative care into existing services. To overcome knowledge and practice deficient of nurses, health policy maker, FMOH, Addis Ababa Health Bureau and educators has to develop curriculum for nurses and develop guide line used for pediatric palliative care.

Understanding poor palliative care knowledge of the nurses as risk factors is key to develop clear and effective strategy for improving child health.

CHAPTER VII QUALITATIVE DATA RESULT

Demographic Characteristics of the FGD Participants

Focus group participants were 23 in number, equal number female and male. Discussion takes 80 minutes. Place of discussion and number of participants were in three areas, Black Lion referral hospital, eight participants, Yekatit 12 hospital eight and Betel Teaching seven. During discussion tape-record was used. Words from tape-record coded and transcribed according its theme. Later described accordingly.

1. What is pediatric palliative care?

The focus group discussion participants define pediatrics palliative care as follows.

"It is a care which is given for the child who has chronic diseases." Other nurse said is care need to support the patient when the patient cannot control himself in case of long standing illness. pediatric palliative cares pertaining to children. When children are sick chronically they need follow up and observation so, this is said palliative care".

Other focus group participant said *"Exact meaning of palliative care is not clear to me it is similar to nursing care. To define pediatric palliative care it needs experience and adequate knowledge in the field of nursing. Pediatric palliative care is not applied in the hospital I am working."*

Other focus group discussant nurse participant describes *" pediatric palliative care seems special care given to the child who have long standing diseases like congenital anomalies (Cerebral Palsy). It is special field of care which needs training he said."*

One of focus group discussant defines pediatrics palliative care *"When I said pediatric it is a branch of science which include medical, surgical treatment as well study growth and development of children. Pediatric palliative care to me is when children became sick with*

life threatening disease; care will be given by specialized nurse or physician. Palliative care means of controlling or alleviating symptom of disease until death appears.”

Finally all groups conclude to define pediatric palliative care, by saying *“it promotes holistic care for children who have life threatening illness that limit survival to adult hood. To give care to children is responsibility of all health worker with special field of study like psychiatric nursing, speech therapist etc. Over all it is team approach pediatric palliative care can be given at home in the community depending on family wishes .they said”*

The reason, why all participants had incoherent definition of pediatrics palliative care is, pediatric palliative care is the new emerging topic.

Nurses play a central role in pediatrics palliative care and end – of – care. Nursing roles include developing plans of care, providing leadership and for children and families. However not all nurses are knowledgeable about the definition of pediatric palliative care. In this research response rate to define palliative care is 68.7%.So nurses are inadequately prepared during their basic education. Pediatric palliative care was not incorporated in bachelor of nurse’ curriculum.

The WHO defined pediatric palliative care as the active total care of the child’s body, mind and spirit. Health care providers must evaluate and alleviate a child’s physical, psychological and social distress. The definition emphasizes that palliative care begins at the time of diagnosis and continues regardless of whether or not a child receives disease directed treatment. Such care encompasses a broad, multidisciplinary approach that includes both the family and the community and is provided in a range of settings from hospital, to clinic, to home and implemented even if resources are limited.

2. How do you assess children with pain?

Focus group discussant describes *“Pain is unpleasant condition to the person feels pain. Pain assessment in infant and children is too different and difficult”*.

“Because children cannot or do not report pain consistently to the nurse. Nurses must follow child’s condition Understanding behavior of the child is important. Observation of child condition and information of parent help us. Currently pain assessment by nurse is limited.

Our Knowledge of pain assessment is based on history taking from parents, doing physical examination and sending the child for laboratory investigation help us to treat. Yes it is clear there are different tools for pain assessment as to me none of us is using it."

"Pain is stressful child with pain may become restless, crying and irritable."

The majority of focus group participant agreed that *"Pain in children must be assessed at regular interval because children cannot report pain .Pain assessment in children is not straight forward as an adult .parents frustration, restlessness and irritability of children create is mind not to assess but to relief the child from pain due to this problem assessment rather than observation is not in our mind."* As majority of my group says we are not used pain assessment tool .We are poor to the application of different assessment tool because there is shortage of time. Again it is not applicable by many health workers. We hope we implement for the future."

It is clear that all children with pain cannot report pain. Considering, observation as only assessment tool may predispose nurses to subjective. Children with different age group manifest pain differently according to their age and developmental level over all, whole body movement refusals of feeding or eating less, playing less, irritability, crying more are some to describe pain in children. In general as a nurse pain assessment tool application needs ample of time, but observing activity of the child, like facial expression, leg movement of neonate in case abdominal cramps are some indicator of pain.

3. Is provision of care based on child's need or on families' information?

All focus group discussant agreed on *"role of families to rear children"*. Families are core for every aspect of care of children; traditionally the family has been considered the basic unit of human society. Family's role is universal their need is to protect children from unwanted problem which can arise. Physical growth and mental maturation and development of children are the outcome of the family. *"All the time the information we get from the parents is said to*

be true.” On the other hand what the children say has to be recognized. Age of the child is one factor fulfills the need of a child. Reliability of information gives clue, for example the child whose age is five can witness in court. Both families and child’s information must go parallel.

They said," As a nurse when we ask to get information about the condition of the child, families response is believed it is true .For example during history taking and physical examination parents appears as informant. This enables the nurse to reach to the diagnosis of the child on the provision of care. During assessment the nurse asks a lot of things like milestone of development, communication skill, behavioral development and maturation and social interaction are some .Need of children are many. The child may refuse important care or need from which she/he benefits because of fear or immaturity. To the opposite, unrealistic needs which have an effect on the child be avoided.

Finally the point of agreement “*on provision of care is based on families’ information and child’s need is to age specific they said.*”

“Good nurses’ relationship with families and the child benefits both parents and children. Caring nurses has knowledge how to approach sick and well child and families’ .We can conclude care provision based on both need which is positive.

The Children’s Act 38 of 2005 section 10 provides a legal obligation to ensure Child Participation and states:

Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration. Furthermore, such information must be given in a way that the child can understand and express their opinions and feelings, which in turn must be taken into account in any decision-making. This means that even when the child is dependent on his/her parents and they may consent on the child’s behalf, the child still has a right to participate in the decision. A child should be provided with important information in a child-friendly manner and his/her opinion.

In palliative care, children who are partners in their own health care should know the basic facts about their illnesses or condition. Important information that has be communicated in

appropriate ways. They know what treatment and care they should have and how important it is.

4. What is your opinion if pediatric palliative care incorporates as field of specialty in nursing education?

Among the respondents one of them said *“education is the best health strategy, as recommended by the World Health Organization (WHO), offers the best approach for translating knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in need of health care. in developing countries was communicable disease, war and disaster are common”*.

Other focus group discussant agreed on the previous point and they said *“an education policy of our country is good but the way individual is recruited is not clear. Education policy makers, health care workers, and the public; has to discuss about the provision of health care, patient care in different health setting of the country .From community point, what does they benefit from health service providers? What do they lack? Policy makers and Ministry of health must evaluate and supervise continuously ,knowledge, attitude and practice of health workers used to revise and implement new educational health curriculum .*

“A Health worker has initiation to learn after serving two years from graduation in governmental institution. This lessens number of worker who resigns from work they said”.
Pediatric palliative care is new merging field of specialty for nurses in the world. In our county if we had this field it is important to give care for children as well for adult patients.

“Implementation of palliative care services at all levels throughout the society education of health care workers has a great influence on their knowledge, which acts as a foundation for better clinical practice. Finally they agreed on continues on job education.”Incorporation of palliative care as field of specialty for nurse has great advantage, Patient can benefit more, minimize longer stay in hospital, shorten hospital bed occupancy as well the service can be

given at the community they said". We all agreed to the incorporation of pediatric palliative care to nursing curriculum as field of specialty."

While many health care disciplines are concerned about improving care at the end of life, the nursing profession is particularly well suited to lead these efforts in view of the scope and standards of advanced practice. Nursing's social policy statement indicates that nurses "attend to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation; integrate objective data with knowledge gained from an understanding of the patient's subjective experience; apply scientific knowledge to the processes of diagnosis and treatment; and provide a caring relationship that facilitates health and healing."

5. What barriers you face to manage pain in children?

They said that "Barriers to pain management in children are many and include inaccuracies regarding mechanisms of pain with statements such as concepts "children do not feel pain the way adults do", "fears regarding the use of tablets, parenteral injection agents and deficits in knowledge of methods of pain assessment. Other factors such as personal values and beliefs, and confidence prevent adequate identification and alleviation of pain for all children." There is different ways of pain management in children like distracting, massaging, positioning this is more time consuming to us."

"On the other hand some of us have poor relationship with parents to communicate about children's condition. Again the environment where we are working is not inviting one. In hospitals we consider that physicians are responsible for assessment and diagnoses. Parents are reluctant, to have their children receive pain medication, this might be fear of side effect of medication or lack of reliability on nurses skill fullness."

CHAPTER VIII STRENGTH AND LIMITATION OF THE STUDY

STRENGTH

1. The instrument used for knowledge assessment is internationally tested one.
2. The study leaves potentially useful background and data for nurse researcher and educators.
3. Triangulation of the qualitative data with to increase the quality of the research.
4. It dealt with important component of child health care that is pediatric palliative care services.

LIMITATIONS

1. Shortage of time. Because each study hospitals IRB wants to review the approved proposal by the school, which takes longer period of time.
2. Scarcity or limitation of similar literatures done in Ethiopia, Africa and other worlds as well to compare and discuss findings.
3. Lack of tools to assess pediatric palliative care knowledge aspect practice and associated factor.
4. In accessibility of pediatrics palliative care ward to observe real practice of nurse
5. Budget constraint.

CHAPTER IX

CONCLUSION AND RECOMMENDATION

The result of this study reveals more than half of the study participants (85.2%) were found to have poor knowledge and (97.5%) poor knowledge aspect of practice on pediatrics palliative care. A life-limiting condition is any condition in a child where there is no reasonable hope of cure and from which the child will die, conditions for which curative treatment has failed e.g. cancer, irreversible organ failure. Conditions associated with periods of normal childhood activities, which usually require long periods of intensive treatment, but which are often associated with premature death e.g. cystic fibrosis, muscular dystrophy. Pediatric palliative care services should be available to all children as required, regardless of their diagnosis or the location of their care. Caring for someone with a life-limiting condition can be challenging on both an emotional and practical level. However, caring for a child or adolescent with a life-limiting condition requires specific knowledge and practical skills. This study showed knowledge, practice, and training deficit of nurses to give pediatrics palliative care.

RECOMMEDATIONS

- ✓ Strategies must be designed by Health policy makers, to amalgamate pediatric palliative in to national health policy.
- ✓ Federal Ministry of Health should consider basic education and on job training need for nurses working in governmental and nongovernmental hospitals to provide standardized pediatric palliative care to children.
- ✓ Federal Ministry Health has to develop standard practice guide line on pediatrics palliative care.
- ✓ Pediatric palliative care should be incorporated to under graduate and post graduate curriculum.

- ✓ Furthermore, studies needed in this area and the government insight to understand life limiting condition problem of children and provision pediatric palliative care according to the context of Ethiopia.
- ✓ Since pediatric palliative care is multidisciplinary approach FMOH, Addis Ababa Health Bureau has to provide regular training.

Reference

1. Wondemageghu Tigenhe, et,al Palliative care Morphine Administration practical guide line Version 1. 2011 Ethiopia
2. Palliative History[Internet] 2011,Avaliable from :[https ://donate Wikimedia.org /wiki /special](https://donate.wikimedia.org/wiki/special)
3. Eleen R.shea et,al Journal of Pediatrics Oncology Nursing ,by Association Pediatrics/ Hematology oncology Nurses 2013 SAGA 30(1) pp34-44
4. Africa Palliative care Association ,Guide line for using APC Africa palliative scale ,Uganda ,Kampala . (APCA) 2012 pp(25-26)
5. Chrisitina Rasco ,Baggote Katherime, Nursing of children and adolescent with cancer 3rd edition ,2002 W,B SAUNDERS COMPANY . Philadelphia
6. Faith Crozier ,Lauren E Hancock ,Pediatrics Palliative Care Beyond the End of life ,Pediatrics Nursing ,July – August 2012 vol.38 /No 4
7. Erin Bleck 04 Nurses attitude Knowledge and use of Non pharmacological pain management ,Techniques and therapies 2004,Illinois Wesleyan University Digital Commons @Ivvil
8. Carers and Friends , The cancer Council NSW 2009 ,Understanding Palliative care , A guide for people with cancer , their families careers and friends 2011. ISNB 978 4
9. Cancer pain relief and palliative care in children , World Health Organization , 2013, pp85 Non serial publication. Geneva
10. Richard Hadge professor Lorraine Sherr ,Dr Rene Alebrtyn , The status of pediatrics palliative care in sub Sahara an Appraisal , University of London. 2010,
11. Hiwot Kassa Woreta , Assessment of Knowledge , attitude ,practice associated factors towards palliative care among nurses working in selected Hospitals at Addis Ababa, Ethiopia 2012.

12. Amy A. STAHLEY Knowledge back ground, and perception ,pain and palliative care giving May 2010 Ball state University. Indiana.
13. Saskia, Jünger ,Andera E Vedder Sigurd Milde ,Pediatrics Palliative care by pediatrics Nurses ,2010 ,Department of palliative Medicine ,RWTH Aachen University Hospital ,Pauwels Istra Be 30,52075 Aachen Germany .
14. Kathy Pnthard ,Jones Rob Pieters , Gorge H Reaman .Improves cancer care for children and young people 2013,www.Health care .com /oncology institute child Health University College , London 15
15. Jakson Orem ,Infection –related cancer in Africa a new paradigm for prevention and control efforts ,2012 common wealth Health partnership.
16. Caprice Knap Vanessa ,et,al Pediatrics palliative care Gblal prospective ,2012 Springer Dordrecht Heidelberg ,London.
- 17.Sonja McIlfatric ,Heelen Nobel , Palliative Medicine Exploring public awareness and perception of palliative Sep,2013 , SAGE
18. Judth A Paice, et,al Global Effect to improve Palliative Care, January 2008.Journal of Advanced Nursing Volume 61Issue 2 pp173-180,
19. Julia D Downing, et, al Developing children’s Palliative care in Africa, BMC palliate care 2013, PP19.
20. Australian Department of Health Sept,2009, Pediatrics Adolescent Palliative care Moc. State of western Australia
21. Cecilia Sepulveda, Amanda Marlin. Palliative Care: The World Health Organizations Global perspective. Journal of pain and symptom Management. August, 2002 vol.24
22. Sharon L Docherty, Cheryl Thaxton .The Nursing Dimension of Providing Palliative Care to Children and Adolescent with cancer, Journal of Clinical Medicine Insight: Pediatrics 2012:6 pp75-88

23. PHIHIP A .PIZZO .DAVID G.POPLACK, Principle and Practice of Pediatrics Oncology 2001 ,5th Edition .Lippincott Williams and Wilkins.
24. Seada Nair, et, al pediatrics pain physiology ,Assessment and pharmacology, July 28,2013.
25. Benita Wilson Nurses' Knowledge of pain. Journal of clinical Nursing, 2007 ,16 1012-1020 Black well Publishing Ltd ,
26. ekatensan preon, Study of Knowledge about palliative care . Indian Journal of palliative care, 18(2) 122-127, May- august ,2010
27. lynnClark Callister ,Global pediatrics palliative care , The American Journal of Maternal /child nursing ,Oct 2007 vol,32 number 5 PP 323
28. Addis Ababa University Medical Faculty Tikure Anbessa Specialized Hospital A 34 years Journey/April 2008 (1-16)
29. IVANKA OZANIC Nursing History in Ethiopia (1961) Ethiopian nurses Association.
30. Linda J.Kristjanson , Samar Aoun And Marianne B. Phillip ,Supportive and palliative care needs of families of children with life –threatening in western Australia: Palliative Medicine 2007 21 :689
31. Hannah K. Reynolds, Palliative Nursing Care in pediatric oncology, 2011 , Liberty University
32. Rn.AMN Health care Education Service, Pain Assessment and Management, 2013
33. Jane W.Ball Pediatric Nursing caring for Children 2003, (3rd edition) Prentice Hall Health ,Washington D C
- 34, Mercedes Stanley, Deborha Pollard. Relationship Between Knowledge ,Attitude , and self efficacy of Nurse in the Management of Pediatrics pain .Pediatrics Nursing July –August 2013 /vol.39No4 (165-171)

35. Margaret M.R. The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurse's knowledge of palliative care. *Journal of Advanced nursing* 1996; (23) 126-137
36. Sadeer G Al –Kindi, palliative care Knowledge and attitude among oncology nurses in Qatar ,2012. Sage publisher
37. Lynn Clark Callister The American Journal of Maternal/Child Nursing Oct,2007 Vol.32 Wolters Kluwer Health LWW No5 PP323 -323 2014
38. Amy AStahaley,Pain and Palliative care May, B State University,MUNCIE,INDIANA, 2012
39. Yarrow Mc Connel Decision Making in pediatric palliative care,Module12.Jan,2005 University of Toronto
40. Donna L Johnson , Availability And Use Of Palliative Care And End –Of –Life Service No ,401 Smyth Rd, Ottawa, Canada, 2008,http://www.djohnston_@cheo.on.ca Accessed on, March 14,2014
41. Laurence Marits, et, al, Asynthesis of the literature on Breaking Bad News or Truth Telling Indian Journal of palliative care V19 (1) Jan –Apr ,2013.
42. Kappa Caprice ,et, al Pediatric nurses' knowledge of palliative care in Florida International Journal of palliative care nursing Sept,2009 ,vol,15 Issue 9,. P432-439. Florida, USA

Annex I English version

Information Sheet and consent

ADDIS ABABA UNIVERSITY COLLEGE OF HEALTH SCIENCE DEPARTMENT OF NURSING AND MIDWIFERY

This is a study done for partial fulfillment of second degree in child health nursing at Addis Ababa University college of Allied Health Science Department of Nursing and midwifery, Graduate studies program, currently I will be undertaking research on topic entitled Assessment of nurses knowledge and practice and associated factor towards pediatrics palliative care of nurses at selected hospitals of Addis Ababa ,Ethiopia.

For this study, you will be selected as a participant and before getting your consent or permission of your participation, you need to know all necessary information related to the study. Thus, this information will be detailed as;

Objective: Assessment of nurses' knowledge and practice and associated factors towards pediatrics palliative care of nurses working at selected hospitals in Addis Ababa.

Duration: The duration of this study will be from March 1 to April 10, 2014

Significant of the study: In many other areas of the world pediatric palliative care is uncommon. It has been estimated that two-thirds of adults and children who need palliative care live in developing countries that have less than 10% of the world's resources. (Rajagopal, Mazza, & Lipman, 2003). Ethiopia is among thus countries .Children's Hospice International (<http://www.chionline.org>) estimates that globally, 7 million children could benefit from palliative care.

The finding of this study may contribute to a better understanding of nurses' Knowledge, of pain assessment and management, as well as improves the standard of practice of palliative and end -of- life care. It is helpful to nurse educators to give great emphasis of what palliative

nursing care and end-of –life care and can be used to support and design program development for staff nurses and nursing students.

In addition, it is helpful for further research, and provides insight to Federal Ministry of health, health policy makers, health bureau administrator who is in quest to improve pediatrics palliative care services, family satisfaction in the study hospitals. This could also serve as the base line and be helpful for improving the palliative care nursing service in Ethiopia. It is helpful to develop curriculum to train nurse student as field of specialty.

There is no research done on this topic in the study area .So, other interested can further use as base line reference. There is no progress in pediatrics palliative care service provision in comparison to that of adult palliative care.

Participants to be included: All nurses who assigned to work in pediatrics ward in selected hospitals of Addis Ababa and who consented to participate in the study.

Confidentiality: All information you give will be kept confidential, and you are not mentioned (indicated) by name and won't accessible to third party. Your name won't register on the question sheet so that you will not be identified. Regarding the predictable risks related to this study, except the time you spent with us no risk at all.

Benefits: For your participation in the study no payment will be granted or has no any special privilege to you .But ,participating in the study and giving your information to questions asked will have great benefits to the society .The result will be used to appeal to those in charge to make in sight of advantage of pediatric palliative care at the state and federal level to pay increased attention to in corroborate in the curriculum of nursing, to open as field of specialty for nurses education and also by participating you will contribute to improvement in the quality of service in the further.

Consent: Your participation in the study will be totally base on your willingness. You have the right not to participate from the beginning, or stop any time after starting participation. You will not force to respond to the information you do not know.

Name of principal Investigator:

Alemnesh Mandesh Date _____ Signature _____

Address Mobile: +2510911872040

E- mail: alem 3217@ yahoo .com

Consent

Addis Ababa University School of Allied Health Science Department of Nursing and Midwifery. Informed consent form.

Greeting, Well come to structured question. First, we would greatly approach for devoting this special time with us.

This is a study done for partial fulfillment of second degree in Child Health Nursing.

To this end, the researcher prepared structured questionnaire, which are presented to you to assess Nurses knowledge and practice pediatrics palliative care totally took about 20 minutes.

Indicate the importance of nurse's knowledge palliative care in the roles assumed by nurses.

You are kindly requested to answer honestly, because it will help all of us having better understanding talking appropriate measures about the situation.

All information you give will be kept confidential, and you are not mentioned (indicated) by name. But the processed general information will be sent for publication and A.A.U.

regarding the predictable risks related to this study, except the time you spent with us no risk at all. More over no immediate benefit will be seen but in long run, it has so many green lights. Includes it plays a great role for policy making, inputs for researchers on this issue and also enhance the development of nursing profession. Responding to the questions is totally

depends on your willingness either to administer or not. If you have any question or more clarification, you can ask supervisor or the principal investigator.

Principal investigator: Alemnesh Mandesh kittle

Address: Addis Ababa University Allied Health Science Department of Nursing a
Midwifery

Phone No: +251-911-872-040 email: alem3217@Yahoo.com

I have understood the condition stated above and I am willing to participate in the study

Yes! Go to the next Page.

No! Thank him/her and interrupt the process.

Researcher Name-----Signature: _____ date _____

Witness name _____ signature: _____ date _____

Part II Amharic version information sheet and cosent

በቅድሚያ ከዚህ ጥናት ላይ እንድሳተፍ በአክብሮት እጠይቃሁ።

ይህ ጥናት እየተካሄደ ያለው በአ.አ. ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ በነርስግና በሚድዋይሬሪ ትምህርት ክፍል በህጻናት ጤና (child health) ድህረ ምቃ ፕሮግራም ዘርፍ ነው።

የጥናቱም ርዕስ፡- ህፃናት በህክምና ስቃይ እንዲሁም ለህልፈተ ህይወት የሚዳርግ በሽታ ሲይዛቸው ነርሶች በእውቀትና በተግባር ላይ የተመሠረተ እንክብካቤ ለመስጠት ያላቸውን ክህሎት ሚመለከት ነው።

Assessment of nurses knowledge & practice on pediatric at selected hospitals of Addis Ababa.

ይህም የምርምር ጥናት በአዲስ አበባ ከተማ በተመረጡ ሆስፒታሎች ህፃናት ክፍል ውስጥ የሚሰሩ ነርሶች ላይ የሚወሰድ ናሙና ነው። በጥናቱ ውስጥ ያሉት አስፈላጊ መረጃዎች እንደሚከተለው እገልጻሁ።

1. የጥናቱ አላማ ነርሶችን እውቀትና ተግባር በህፃናት ሚደርሰውን የህመም ስቃይ ላይ እንዲሁም ለህልፈተ ህይወት ከመዳረጋቸው በፊት የሚሰጠውን እንክብካቤ ይመለከታል።
2. ጥናቱ የሚወሰደው ጊዜ 20 ደቂቃ ሆኖ ወቅቱም ከመጋት እስከ ሚያዝያ 30/2006 ዓ.ም ድረስ ነው።
3. የጥናቱ ጭብጥ፣ ይህ ጥናት በሌላም ዓለም ክፍል በብዛት አልተወራም። ይሁን እንጂ እንደ ኢትዮጵያን እያደጉ ባሉ ሀገራት ውስጥ በሚገኝ ህጻናት ለሚደርሰው የህመም ስቃይ፣ የአድሜ ልክ በሽታ፣ እንክብካቤ ህፃናት ህፃናቱ እንዲገኙ ይረዳል።

ሀ. በዚህ ጥናት ውጤት ነርሶች በዚህ መስክ ለወደፊት እውቀትን በመጨመር ህመምን እንዴት እንደሚቆጣጠሩ ይገመግማል አሁን ያለበትንም ሁኔታ ያስረዳል።

ለ. በተጨማሪም ይህ የምርምር ጥናት ወደፊት ምርምር ለሚያደርጉ መነሻ ሀሳብ ይሰጣል።

ሐ. ለፌደራል ጤና ጥበቃ ሚኒስቴር፣ ለጤና ፖሊስ አውጪዎች፣ ለጤና ቢሮ ሀላፊዎች ሌቤተሰቦችም ጭምር ባለሆነ ህመም (cancer HIV /ADIS, congenital anomalies) ለሚሰቃዩ ህፃናት የጤና እንክብካቤ እንዲሻሻል ግንዛቤ ይሰጣል።

መ. በኢትዮጵያ ውስጥ በማይድን በሽታ ለተጎዱ ህፃናት እስከ ጊዜ ሞታቸው ድረስ መረዳት የሚቻልበትን ቦታ በማን እርዳታ ማግኘት እንዳለባቸው ለወደፊት ግንዛቤ ይሰጣል።

ሠ. በነርስነት ትምህርት መርሃ ግብር ተቀርፆ (cuiculum) በነርስነት በዚህ ትምህርት ልዩ ስልጠና እንዲያገኙ ይረዳል።

4. ምስጥራዊነት፡- ይህ ጥናት ምስጥራዊነቱ የተጠበቀ ነው። 1 የምትሰጡት መረጃ ለሶስተኛ ወገን ተላልፎ አይሰጥም። በመልስ መስጫ ወረቀት ላይ ስም መፃፍ አያስፈልግም። ስለዚህ ላይ ጥናት የሚያስከትለው ምንም ዓይነት ችግር የለም።

5. በዚህ ጥናት ለመሳተፍ ቀጥተኛ የሚባል ጥቅም የለውም ሆኖም ግን ለህፃናቱና ለህብረተሰቡ ለወደፊት መሠረት ጣይ ጠቃሚነት ይኖረዋል።

6. ፈቃደኝነትን ስለማቋረጥ፣ በዚህ ጥናት ውስጥ የመሳተፍ መብት ሙሉ በሙሉ በፍቃደኝነት ላይ የተመሠረተ ነው።

አድራሻ ማወቅ ካስፈለገዎ

የዋሃው ተመራማሪ አድራሻ

ስም ዓለምነሽ ማንደሽ ሞባይል ቁጥር 091187-20-40

ኢ-ሜል a/em3217@yahoo.com

ANNEX 2

Addis Ababa University School of Allied Health Science, Department of Nursing and Midwifery

Questionnaire on Assessment of nurses' knowledge practice and associated factors towards pediatrics palliative care on nurses working at selected hospitals in Addis Ababa, Ethiopia

Institution/ Hospital _____

Instruction

This question has two parts each part has close ended questions. All question must be answered .

Part one Socio- Demographic Data

To be filled by nurses in pediatrics ward Affiliation (tick one)

. General information

1. Age of respondent _____

2. Gender

A. Female

B. Male

3. Level of education

A. Nursing Diploma

B. Bachelors in nursing

C. Masters in nursing

.

D. Other field of study certificate / diploma /degree

4. Year of working experiences

A. Less than 5 years

C.11-15years

B. 5-10 years

D.More than 16 years

5. Current working pediatrics ward

A. Medical ward

B. Surgical ward

C. Neonatology ward

D. PICU

E. Neonatology

E. Outpatient Department

F. Pediatrics emergency unit

6. Experience in caring terminal ill child

A. Daily B .Once per week C. Once per Month D. Few times per E. never

7. Have you take training on pediatric palliative care?

1. Yes B .No

If yes how long you had

A.1-2 week B. 1 month C.6 Month D. Never

5. በአሁኑ ወቅት እየሰሩ ያለበት ክፍል

ሀ. የውስጥ ደዌ ክፍል

ለ. ቀዶ ህክምና

ሐ. የጨቅላ ህፃናት

መ. የህፃናት ልዩ ጥንቃቄ ህክምና ክፍል

ሠ. የተመላላሽ ህክምና

ረ. የህጻናት ድንገተኛ

ሰ. የህጻናት ካንሰር ህክምና

6. በጣር ላይ ላለ ህጻን እንክብካቤ የማድረግ ልምድ

ሀ. በየቀኑ

ለ. በየሳምንቱ

ሐ. የወሩ አንድ ጊዜ

መ. ጥቂት ጊዜ በዓመት

ሠ. ፈፅሞ አልተላለፍኩም

7. የህፃናትን ህክምና ለማስታገስ ስልጠና ወስደዋል?

ሀ. አዎን

ለ. አልወሰድኩም

8. ስልጠና ወስደው ከሆነ ለምን ያህል ጊዜ?

ሀ. ከአንድ እስከ ሁለት ሳምንት

ለ. ለአንድ ወር

ሐ. ለስድስት ወር

መ. ፈፅሞ አልተሳተፍኩም

Part II Questionnaires English Version

Palliative care quiz for nursing (PCQN)

Write X for the answer you choose for respective question

No	Characteristics	YesN (%)	No N (%)	Don't Know N (%)
1.	Do you know the definition palliative care?			
2.	Palliative care is only appropriate in situations A downhill trajectory or deterioration conditions			
3.	The extent of the disease determines the Method of pain treatment			
4.	Adjuvant therapies are important in managing pain			
5.	Drug addiction is a major problem when morphine is used on a long- term basis for the management of pain			
6.	The provision of palliative care require emotional detachment			
7.	During terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea			
8.	The philosophy of palliative care is compatible With that of aggressive treatment			
9.	The use of placebo is appropriate in the treatment Of some type of pain			
10.	Mepridine (Demerol)is not an effective analgesics For the control of chronic pain			
11.	The accumulation of loses renders burn out inevitable for those who work in palliative care.			
12.	Manifestation of chronic pain are different from those of acute pain .			
13.	Terminally ill children families have the right to choose “ Do not resuscitate (DNR)			
14.	Families of terminally ill child should have hope against all odds			
15.	Increase in Vital sign help as pain assessment tool			
16.	Because their nervous system is underdeveloped, children under two years of age have decreased pain sensitivity and limited memory of painful experiences.			
17.	Children who can be distracted from pain usually do not have severe pain. Patients may sleep in spite of severe pain.			

ክፍል 2

በህመም ስቃይ ላይ ለሚገኙ ህፃናት በሚሰጥ እንክብካቤ የተዘጋጀ መጠይቅ መልስ መስጫ መልስ በሚሰጡበት ወቅት ይህንን X ምልክት ተጠቀሙ።

ተራ ቁጥር	ዓይነት	አዎን %	አይደለም %	አላውቀውም %
1	የህፃናት ሀይለኛ የህመም ማስታገሻ እንዴት ይገለጻል።			
2	በሀይለኛ ህመም ውስጥ ላይ ህፃናት እንክብካቤ መስጠት ያለበት ህመሙ ሲፀናባቸው ሁኔታው ሲባባስባቸው ነው ወይ?			
3	የበሽተኛው የህመም አይነት የሚሰጠውን የመድሀኒት አይነት ይወስናል።			
4	ከህመም ማስታገሻነት በተጨማሪ የሚሰጡ መድሀኒቶች ህመምን ለመቆጣጠር ይጠቅማል።			
5	ሞርፍን የተባለውን መድሀኒት ለህመምተኛ ለህመም ማስታገሻነት ረዘም ላለ ጊዜ መስጠት ሱስ ሊያስይዝ ይችላል።			
6	ሀይለኛ የህመም ስሜትን ለማስታገስ የሚደረገው ስሜት ስለሚነካ ገለልተኛ መሆን አስፈላጊ ነው።			
7	በጣር ላይ ላለ በሽተኛ የመተንፈሻ አካል ስራ ሲቀንስ የሚሰጥ መድሀኒት በሌላ መልኩ ሀይለኛ የትንፋሽ መቆራረጥ ላለበት በሽተኛ ቢሰጥ ይጠቅማል።			
8	የህመም ማስታገሻ ፍልስፍና ሀይለኛና ከሚጎዳ መድሀኒት ጋር ይነፃጸራል።			
9	በሽተኛውን ለማስደሰት የሚሰጥ እውነተኛ ያልሆነ የህመም ማስታገሻ መድሀኒት ለተወሰነ ህመም ፈቃድነት አለው።			
10	መፕሪድን (ደሚርስ) መድሀኒት ለረጅም ጊዜ የቆየን በሽታን ለመቆጣጠር ውጤታማ መድሀኒት አይደለም			
11	ለብዙ ጊዜ ክፍተኛ ህመም ማስታገሻ የሚሰጥበት ክፍል ውስጥ መስራት መረገምና የማይቀር የማይጠረጠር ነው			
12	የቆዩ በሽታ ምልክት ከአዲስ የበሽታ ምልክት ጋር ሲነፃፀር ልዩነት አለው			
13	በጣር ላይ ለሚገኝ ልጅ በህክምና ህይወት እንዲዘራ ሲደረግ ወላጆች መረዳት ያለበትም የማለት መብት አላቸው።			
14	በክፍተኛ ህመም ውስጥ ላለ ልጅ ወላጆቹ ማንኛውንም ሊከሰት የሚችል እኩይ ችግሮችን መቀበል ግዴታ አለባቸው			
15	ህመምን ለመፈተሽ የልብ ትርታ የመተንፈስ ሁኔታ የደም ግፊት እና የሰውነት ትኩሳት መጨመር አይነተኛ መሣሪያ ሆኖ ያገለግላል			
16	ከሁለት ዓመት በታች ያሉት ህፃናት ነርቫቸው ባለመበልፀጉ ያነሰ ህመም ስሜት ይኖራቸዋል እንዲሁም ህመም የማስታወስ ስሜታቸው ያነሰ ይሆናል።			
17	ልጆች ሀይለኛ ህመም ሲሰማቸው ህመሙን በማባበል እንዳያስታውሱ በማድረግ እንቅልፍ እንዲወስዳቸው ይደረጋል			

ANNEX III

Part I. Practice questionnaires (Knowledge aspect practice of nurses)

Choose the best answer /answers for the following questions

1. When do you institute palliative care discussion?
 - A. During diagnosis
 - B. when the disease progress
 - C. At the end of life
2. Do you inform to the family their child's is terminal stage?
 - A. Yes
 - B. No
 - C. Depending on family's wishes
 - D. Inapplicable
3. What are the factors you consider when dealing with the family terminally ill child?
 - A. Spiritual /religious
 - B. Medical situation
 - C. Cultur
 - D. Psychological conditions
4. How would address spiritual issues and your concerns to the child's family
 - A. Connect with spiritual counselor or pastoral care according to the child's religion and wish of the family?
 - B. Listen with empathy
 - C. Impose your own view
 - D. Understand child's family reaction to the to the losses of their child's life
5. Culture assessment during child care should include
 - A. Truth telling and decision –making
 - B. Preferences regarding disclosure of information.

C. Perspective of death ,suffering

D. Perspective of death ,suffering

E. Perspective of death ,suffering

6. How do you address psychological issues of the child during child care

A. Emotional support

B. Counseling child's family

C. Play with child according to age

D. Hide the truth about prognosis of the disease

7. In your current practice whom do you involve in the decision-making process related child condition?

A. Child according to age

B. Family

C. My own

D. Other health professional

8. Do you perceive the families of terminally ill child or the child as his age when they ask questions or concern as about their condition as

9. Information communication to the family of the terminally ill child depends on

A. Family's ability to assimilate

B. Their involvement of decision making

C. Your willingness to disclose information

10. Types of pain medication /analgesics commonly used in your practice for Pain

A. Paracetamol suppository syrup

B. B. Codeine

C. C. Morphine

11.How do you assess children pain?

A.Using tools for assessment

B. observation

C. Grade with face

D. Intensity

ክፍል 2

አዲስ አበባ ከተማ በተመረጡ ሆስፒታሎች ውስጥ ለሚሰሩ ነርሶች በእውቀት ላይ የተመሠረተ የተግባር ክህሎትን ለመፈተሽ እና የህመም ማስታገሻ መድሀኒት መስጠት ህመሙ የሚደበሰበስበትን ልምድ መጠይቅ።

ተራ ቁጥር	ዓይነት	ከሁለት በላይ /መልስ አለው።	አዎ %	አይደለም %
1	ማስታገሻ ለመስጠት ከበሽተኛው ጋር ውይይት የሚደረገው	ሀ. መጀመሪያ በሽታው ዓይነት ሲታወቅ ለ. በሽተኛው ሥር ሲሰድ ሐ. በሽተኛው ለመሞት ሲያጣጥር		
2	ለልጆች ቤተሰቦች ልጃቸው በጣር ላይ ስለመሆኑ ትነግረዋለሽ ወይም ትነግራለህ?	ሀ. አዎን ለ. አልነግርም ሐ. በወላጆች ፍላጎት ላይ የተመሠረተ ነው መ. ተፈጻሚነት የለውም		
3	በጠና ልጃቸው ለታመመባቸው ወላጆች ግንዛቤ ማስገባት ያለብን	ሀ. የመንፈሳዊ ጉዳይ ለ. የህክምና ሁኔታ ሐ. የባህላዊ ጉዳይ መ. የስነ አእምሮ ሁኔታ		
4	መንፈሳዊ ሁኔታን ስናስተውልና ሲገነዘብ	ሀ. በሽታውን ከመንፈሳዊ አማካሪ ጋር ማገናኘት ለ. እኔ ቢሆን ኑሮ ብሎ ማዳመጥ ሐ. የግለሰብን የግል አመለካከት እንዲቀበሉ ተዕዕኖ ማድረግ መ. የወላጆችን አፀገበሮት ሆኑ ማጤን		
5	የልጅን ባህላዊ ሁኔታ በእንክብካቤ ፍተሻ ውስጥ መመልከት ግዴታ ነው ይኸውም	ሀ. እርግጠኛውን ነገር መናገርና ውሳኔ መስጠት ለ. አማራጭን ወስዶ መረጃን ግልፅ ማድረግ ሐ. የምግብ ፍላጎት አማራጭ መ. ቋንቋ ቤተሰብን በንግግር መግባባት ሠ. ክርቀት ሞትን ስቃይን ሀዘንን ማሰብ		
6	የግለሰብን ስነ ልቦና ለማስተዋል የሚደረግ	ሀ. የግለሰብ ስሜት መደገፍ ለ. የልጅን ቤተሰብ ማማከር ሐ. የበሽታውን አካሄድ መደበቅ መ. ከልጅ ጋር እንደአድሜው መነጋገር		
7	ውሳኔ ለመወሰን ማንን መከተን አለበት	ሀ. ልጅ ይገባዋል ተብሎ ከተገመተበት እድሜ ማማከር ለ. የልጅን ቤተሰብ ሐ. እኔ በግሌ መወሰን መ. ሌሎችን የጤና ባለሙያዎች		
8	ልጆች ወይም በጣር ላይ ያለ ልጅ ቤተሰብ ወላጅ ስለልጅ ያለውን ግንዛቤ ጥያቄ ሲጠይቁ	ሀ. የበሽተኛ መብት መሆኑን ለ. ማስፈራሪያ ስጋት መሆኑን ሐ. ባለሙያን ችግር ውስጥ መክተት		

	ትገነዘበዋለህ/ትገነዘቢዋለሽ	መ. የልጅ ወላጆች ትኩረት የመሳብ ባህሪ ነው።		
9	መረጃን በማግባባት ጣር ላይ ላለ ልጅ ቤተሰብ መስጠት ተመሰረተው	ሀ. የቤተሰብ ነገሮችን የመቅሰም ሁኔታ ለ. ወላጆች ውሳኔ ለመስጠት ዝግጁ መሆን ሐ. ባለሞያው ሁኔታውን ለመግለጽ ፈቃደኛ መሆን		
10	በአብዛኛውን ጊዜ ለህመም ማስታገሻነት በአንባቢህ/ሽ/ የምትጠቀሙ የህመም ማስታገሻ	ሀ. ፓራስታሞል በፊንጥጣ የሚገባ /የሚጠጣ/ እቦቡረፈን ለ. ኮድን ሐ. ሞርፍን		
11	በህመም ላይ ያለን ልጅ በየትኛውም ዘዴ ነው የምትፈትሽው /የምትፈትሹው/	ሀ. የተለያዩ የመፈተሻ መሳሪያ በመጠቀም ለ. በማየት ሐ. የልጅ ፊት በማየት የህመሙን ጥልቀት መገንዘብ		

ANNEX IV

Part:I Qualitative interview guide

1. What is pediatrics palliative?
2. How do you assess children with pain?
3. Is provision of on care based on child's need or on family's information?
4. What is your opinion if pediatric palliative care incorporated as field of specialty in nursing education ?
5. What barriers you face to manage pain in children?

ክፍል 2:- ለቃል ጥያቄ ውይይት የተዘጋጀ መመሪያ

1. የህፃናት የስቃይ ህመም ማስታገሻ ማለት ምንድን ነው?
2. የህፃናት ህመም እንዴት ይፈተሻል
3. ለህፃናት እንክብካቤ ስትሰጥ ስትሰጭ በልጅ ፍላጎት ላይ የተመሠረተ ወይንም በወላጆቹ
4. የሥቃይ ህመም ማስታወሻ ትምህርት በነርሶች ትምህርት መርህ ግብር ቢካተት ምን ይመስልሃል /ይመስልሻል
5. የህፃናትን ህመም ለመቆጣጠር ያጋጠመዎት ችግር ምንድን ነው?