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Pediatric Nurses' Attitudes, Practices and Barriers to Palliative Care of Children and their Families

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Pediatric Nurses' Attitudes, Practices, and Barriers to Palliative Care of Children and Their Families

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Pediatric Nurses' Attitudes, Practices, and Barriers to Palliative Care of Children and Their Families

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Dedication

To the teacher of humanity and the first person who brings us out of the darkness to the light; Mohammed bin Abdullah - may prayers and peace be upon our Prophet Mohammed, his relatives and his companions.

To whom I carry his name with pride, to whom I miss from childhood, to those which my heart is wavering for your memory, to my dear father (**Nasser**)

To my angel of life , to the meaning of love…the meaning of compassion

To the smile life and secret of existence, to those whose prayer was the secret of my success, to my (**mother**)

To my dear **brothers Laith, Ahmed, Hussein, Ghayth,** and my dear sister to my heart**, Raheeq** thanks for supporting me.

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To all my friends I would like to thank them for being always beside me.

Declaration

I certify that this thesis submitted for the degree of Master is the result of my own research, except where otherwise acknowledged, and that this thesis (or any part of the same) has not been submitted for a higher degree to any other university or institute.

Signed: Atheer

Atheer Nasser Hussein Qashou

Date : 13 / 5 / 2018

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Allah says " "If ye are grateful, I will add more (favours) unto you"After thanking Allah for his bounty and gratitude and great greatness and generosity of his gift, where he allows me to complete this blessed work is praise and blessings from him.

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Abstract

Introduction: Palliative care (P.C) is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, perfect assessment, treatment of pain and other physical, psychosocial and spiritual problems.

In previous years palliative care was known as the care of the patient who is close to death but now, the capacity of palliative care has expanded to include patients who may live for many years with chronic disease.

Objective: The study aimed to assess practice attitude and Barriers about palliative care among nurses working in Pediatric wards at 12 private hospitals in the west bank, Palestine.

Methods: Descriptive, cross sectional quantitative study design and the stratified sampling procedure were used for conducting the study. Two research hypotheses were addressed by using independent samples t-test, and one way ANOVA statistical analysis. A Sample of 236 nurses working in the pediatric ward from 12 private hospitals was chosen for this study. Data were collected by using questionnaire with demographic data and palliative cares Quiz for Nurses (PCQN) and from melt Attitudes toward Care of the Dying Scale (FATCOD). Pilot study was conducted among 20 nurses.

Result: A statistically significant difference existed between the Palliative Care Quiz for Nurses scores based on gender (p=0.030) and level of education (p=0.017) for the area of relief of pain and other Symptoms solely. Likewise, results of this study revealed that significant differences existed between the nurses’ attitude survey scores according to the number of admissions in all subscale areas including: Holistic Care of the Child (p

<0.001), Support of the Family Unit (p=0.002), Involvement of Child and Family in communication...etc. (p<0.001), Continuity of Care (p=0.001).

Findings did not reveal any significant relationship with the identified demographic variables of employment status, age-group, education, nurses' position and previous experience in the areas of Holistic Care of the Child, Support of the Family Unit, Involvement of Child and Family in communication … etc., Continuity of Care, and Grief and Bereavement Support.

Conclusion: The nurses had poor knowledge, but their attitude towards PC was positivity and favorable. This study ultimately lends support for the inclusion of Palliative Care in nursing education. The responsibility of undergraduate nursing faculty is to ascertain that their curriculum is reflective of current practice needs. Being knowledgeable about Palliative Care can help nurses overcome many of the documented barriers to the management of chronicity in patients toward the end-of-life.

Recommendations are that integration of the national health policy related to PC in the national curriculum of nurse education and provide training related to PC for the nurses.

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Abbreviations.	**Meaning**
AAP	American Academy of Pediatrics
API	Attitude Practice Inventory
BSN	Bachelor of Science in Nursing
EAPC	European Association for Palliative Care
EHS	Electronic health system
EOL	END OF LIFE
EOLC	End-of-life care
FATCOD	From melt Attitudes toward Care of the Dying Scale
FHT	Family healthy team
LLC	Life-limiting conditions
MOHP	Ministry of Health Palestine
MSAS	Memorial Symptom Assessment Scale
NCCNW	The National Comprehensive Cancer Network
NHPCO	National Hospice and Palliative Care Organization
NHPCO	National Hospice and Palliative Care Organization
PC	Palliative Care
PCQN	The Palliative Care Quality Network
PCQN	The Palliative Care Quiz for Nurses
UMMC	University of Maryland Medical Center
WHO	World Health Organization

Chapter one:

Introduction:

1.1 End Life Threatening Condition

Palliative care started with an emphasis on the care of the dying. Dr. Cicely Saunders initially enunciated her thoughts regarding current hospice mind in the late1950s in light of the observation of dying patients. She upheld that lone an interdisciplinary group could ease the "total pain " of a withering individual with regards to his or her family, and the group idea was still at the core of palliative care Dr. Balfour Mount, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal, Canada, instituted the term palliative care to keep away from the negative essences of the word hospice in French culture, and presented Dr. Saunders' advancements into scholastic educating healing facilities. He initially showed what it intended to give all-encompassing consideration to individuals with constant or life-threatening condition and their families who were encountering physical, mental, social, or otherworldly misery(Loscalzo,2008).

In 2006 the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education perceived the subspecialty of Hospice and Palliative Medicine. Palliative medicine is the continuation of the long struggle to recognize life on its own, honestly and straightforwardly. With its place in scientific medication, this new sub-specialty aims to empower future eras of physicians to take palliative care at the generalist level, to advance field learning, and to give our patients and their families our guarantee that we will not deliver them with our medicines fall flat and we will do everything consistently to appease their misery (Loscalzo,2008).

In other hand Palliative care is an approach that improves the quality of life of patients and their families through the prevention and relief of suffering (WHO, 2017).

Given to 4group of children in the accompanying:

- Children with life-threatening conditions: for which curative treatment may be possible but may fail.
- Children with conditions: long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities.
- Children with progressive condition: without the possibility of a cure.
- Children with conditions not usually considered progressive: cause weakness and make children more likely to get complications.

It is always difficult to accept a loved-one’s life-threatening illness or approaching death; acceptance is even more difficult when the patient is a child. (Benner, 2003).

1.2 Statement of the Problem

Palliative care is new concept in Palestine, if applicable will be poorer of quality and services such as: cancer is second cause at all ages in Palestine. It’s about 14.2%, result barriers to service development include ‘‘opioid phobia’’ in professionals, and a continuing lack of awareness and understanding of palliative care needs at professional levels. In the other hand should include in curriculum in college of all healthy team system through especially training to be subspecialty to offer need patient (Khleif, and Dweib, 2015). The Palestinian culture that comes mainly from religion compensates with greater psychological comfort and spirituality, especially for terminal patients. Improving palliative care among Palestinians requires strengthening the positive religious and cultural values in caring for the sick particularly with the new generation where these values tend to weaken with time (Abu Seir, and Kharroubi, 2017).

The outcomes demonstrated that arrangement of brilliant PC administrations requires instruction and preparing medical attendants. The PC should include in all school educational module, and Permanent recommendations for attendants and therapeutic training. Control the usage of the PC conveyance showed which is socially delicate and addresses the issues of the Palestinian population (Ayed et al., 2015). The need for a program that can provide EOL care is noted in the literature with a focus on implementation of palliative care programs and benefits the program will provide for nursing home patients (Hall et al., 2011). The current state of palliative care in nursing homes showed that facilities do not have the education or skills needed to develop and implement a palliative care program despite of they recognized key barriers to palliative care incorporation crosswise over three World Health Organization domains.

1.3 Significance of the Study

Statistics based on the Palestinian Ministry of Health, according to the years, was:

Crude death rate (CDR) in 2012: According to PHIC figures, the crude death rate declined progressively over the years. The crude death rate for Palestine declined from (3.0) per 1,000 of population in 2000 to (2.5) per 1,000 of population in 2012. In Gaza Strip the crude death rate reached (2.4) per 1,000 of population in 2012, while in West Bank the crude death rate reached (2.6) per 1,000 of population in 2012. Infant Mortality: The reported infant mortality rate was (13.5) per 1,000 live birth for the year 2012.

Reported Infant Mortality in Palestine 2016: Reported infant mortality rate in Palestine in 2016 was 10.5 per 1,000 live births. In 2015, the infant mortality rate was 10.9 per 1,000 live births. Less than Five Children Reported Mortality Rate: In 2016, fewer than five children reported mortality rate was 12.2 deaths per 1,000 births. In 2015, fewer than five children reported mortality rate was 13.9 deaths per 1,000 live births in Palestine.

UNRWA marked an important milestone in one of its health reform strategies, the Family Health Team (FHT) approach. In 2016, the FHT approach became operational in all health centers in four fields, Palestine refugees in Jordan, Lebanon, Syria, West Bank, including East Jerusalem and the Gaza Strip achieved their full human development potential, pending a just and lasting solution to their plight. UNRWA services encompass education, health care, relief and social services, camp infrastructure and improvement, protection and microfinance. The approach also included the introduction of e-Health, and together with FHT, this resulted in more efficient services, shorter waiting time, increased patient consultation times, improved health care facilities, and satisfaction from both staffs and patients (Health Department Annual Report 2017 Wednesday, May 24, 2017).

1.4 Aims of the study

Aims of this study were to develop a knowledge base about palliative care practice, attitude in pediatric nursing, thus identifying facilitators and barriers to practice, and; to draw upon these findings to develop policy recommendations to improve this field of Pediatric nurses in West Bank of Palestine to explore the barriers and facilitators to pediatric palliative care practice.

1.5 Objectives of the Study

- To describe the attitudes and practice of pediatric nurses regarding the care of children with life-threatening conditions and their families.
- To assess the level of barriers of pediatric nurses regarding the care of children with life-threatening conditions and their families.
- To examine the relationship in these practices , attitudes and barriers among pediatric nurses regarding to the end-of-life care of children with life-threatening conditions and their selected by demographic variables.

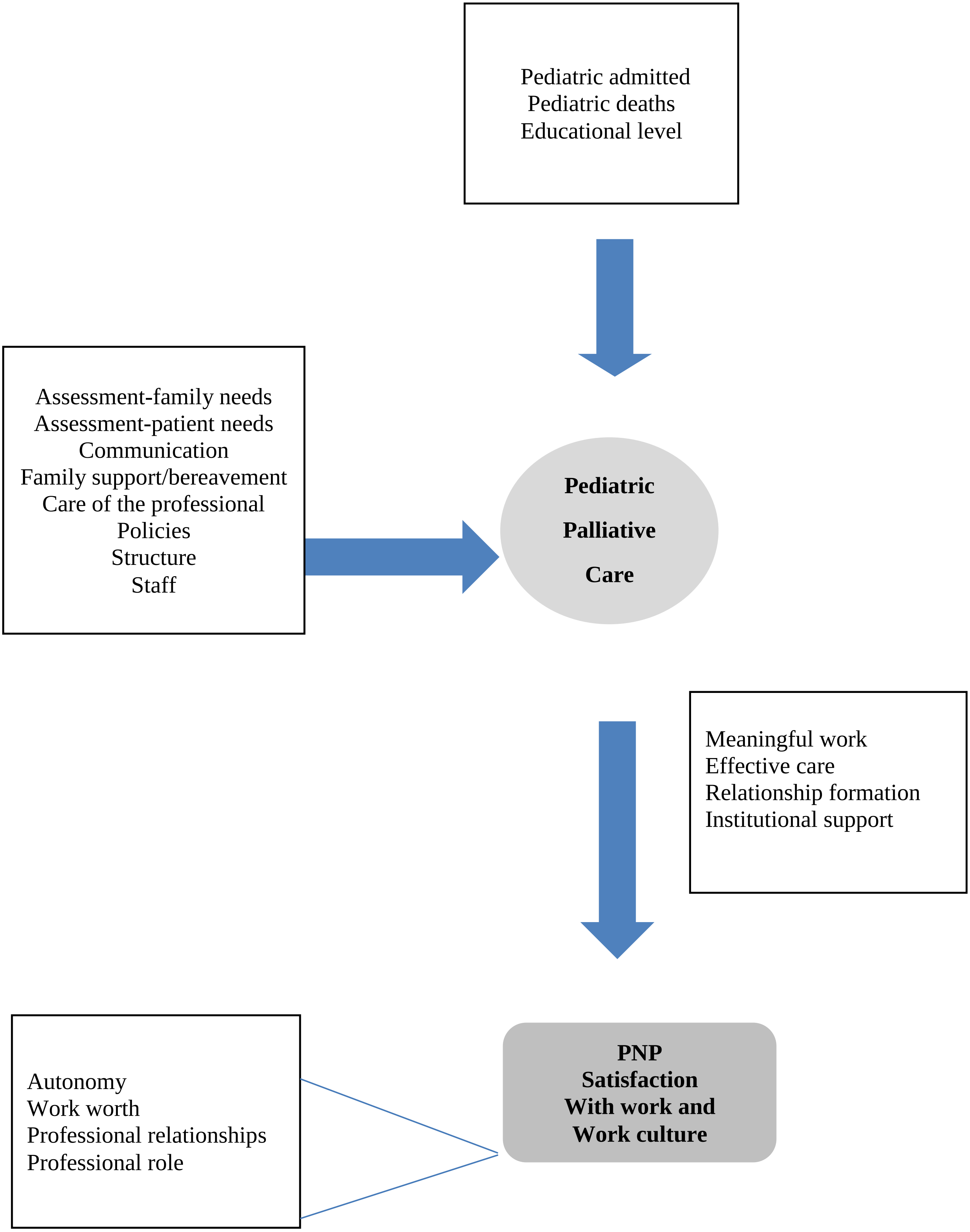
1.6 Questions of the Study

1. What is the level of practice of pediatric nurses regarding to the end-of-life care of children with life-threatening conditions and their families?
2. What is the attitudes' level of pediatric nurses regarding the end-of-life care children with life-threatening conditions and their families?
3. How can we examine the relationship in these practices , attitudes and barriers among pediatric nurses regarding to the end-of-life care of children with life-threatening conditions and their selected by demographic variables?

1.7 Null Hypothesis

1. There will be no significant difference in attitude and practice toward end of life care between pediatric nurses regarding the end-of-life care children with life threatening conditions and their families as measured by the FATCOD scale.
2. There will be no significant difference in barriers of end-of-life care between pediatric nurses regarding the end-of-life care of children with life-threatening conditions and their families as measured by the PCQN.

1.8 Conceptual Framework



Pediatric palliative care is a relatively new clinical specialty. Its nature is multi-dimensional and its delivery necessarily multi-professional. Families with children with life - limiting conditions and complex health care needs require early and ongoing support from diagnosis onwards with their child’s health and social care. Ongoing and timely support was designed to minimize the wider impacts on the family (Chambers et al., 2009).

Based on literatures reviews as well as a discussion of the observations and experiences of who had worked in providing end-of-life care for children with life limiting illness and their families, a simple conceptual framework that and to develop practical procedural guidelines and improve the quality of care of the dying within an ethical framework and through a professional and family/patient consensus process. All factors were theorized in our framework as important in the end-of-life care services. As showed in (*Figure1*). Conceptual framework for an integrated palliative care service Children’s palliative care should be flexible and reactive to the needs of children and parents.

The conceptual framework in (*Figure 1*) showed how environment factors such as, Infants admitted, Infant deaths, Educational level, community awareness, system structure and facilities affect upon palliative care. Also showed how improving process aspects such as, Assessment-family needs care.

Assessment-patient needs, Communication, Family support/bereavement, Care of the professional, Policies, Structure, patient centered, Facilities Staff provider characteristic, the extent of collaboration among providers and information transfer improves the services of life-threatened children.

All mentioned above had an impact on care process, the better circumstances the more positive effects on the process of caring for children; meaningful work, effective care, relationship formation, stress reduction professional relationships, professional role, enactment and other benefits. The conceptual framework suggested it is a necessary condition to improve the system structure and care process to improve the patient outcomes, such as satisfaction with domains of care and access, perceptions of client of care and perceptions of continuity of care.

Chapter Two:

Literature Review:

2.1 Life-Threatening Illness

When people think of the deadliest diseases in the world; their minds probably jump to the fast-acting incurable ones that grab headlines from time to time. But in fact, many of these types of diseases don't rank in the top 10 causes of worldwide deaths. An estimated 56.4 million people passed away worldwide in 2015, and 68 percent of them were due to diseases that progressed slowly. Perhaps even more surprising is that several of the deadliest diseases are partially preventable. Non-preventable factors include where a person lives, access to preventive care, and quality of healthcare. These all factor into risk. But there are still steps everyone can take to lower their risk (WHO, 2017).

Life threatening disease is the diseases which can leads to death of patient. These diseases are very dangerous disease such as cancer, HIV, Heart diseases etc. Mostly chronic diseases are life threatening diseases. Life threatening diseases are chronic, usually incurable diseases, which have the effect of considerably limiting a person's life expectancy. These include cancer, diabetes, neurological conditions, coronary heart disease and HIV/Aids (https://www.omicsonline.org/scholarly/life-threatening-disease-journals-articles-ppts-list.php).

Life-limiting conditions (LLC) in children and young people can be defined as conditions for which there is no reasonable hope of cure and from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail (Fraser et al., 2011). Life-limiting conditions (LLCs) describe diseases with no reasonable hope of cure that will ultimately be fatal. For children with these diseases, palliative care services should be available but few data are available to estimate the burden of these conditions (Fraser et al., 2012).

2.2 Pain management

Pain is one of the most common adverse stimuli experienced by children, occurring as a result of injury, illness, and necessary medical procedures. It is associated with increased anxiety, avoidance, somatic symptoms, and increased parent distress. The pediatric acute pain experience involves the interaction of physiologic, psychological, behavioral, developmental, and situational factors (AAP, 2001).

An important responsibility of health care professionals who care for children is eliminating pain and suffering when possible. However, it is documented that children are often under-treated for their pain (Petrack et al., 1997).

Pain can be measured by self-report (what children say), biological markers (how their bodies react), and behavior (what children do). Pain is a subjective event and so self-report is best, if it is available. Unfortunately, in many infants, young children, or children with cognitive or physical impairments, self-report is not available and behavioral or biological measures must be used (McGrath, 2006). Pain management, pain medicine, pain control or alligator, is a branch of medicine employing an interdisciplinary approach for easing the suffering and improving the quality of life of those living with chronic pain (Hardy, 1997).

The typical pain management team includes medical practitioners, pharmacists, clinical psychologists, physiotherapists, occupational therapists, physician assistants, nurse practitioners, and clinical nurse specialists (Main, and Spanswick, 2000). The term may also include other mental health specialists and massage therapists. Pain sometimes resolves promptly once the underlying trauma or pathology has healed, and is treated by one practitioner, with drugs such as analgesics and (occasionally) anxiolytics. Effective management of chronic (long-term) pain, however, frequently requires the coordinated efforts of the management team (Thienhaus, and Cole, 2002).

There are many types of pain management, and each of them has its own benefits, drawbacks, and limits. A common in pain management is communication. People experiencing pain may have difficulty difficult recognizing or describing what they feel and how intense it is. Health care providers and patients may have difficulty communicating with each other about how pain responds to treatments. There is a continuing risk in many types of pain management for the patient to take treatment which is less effective than needed or which causes other difficulty and side effects. Some treatments for pain can be harmful if overused. A goal of pain management for the patient and their health care provider to identify the amount of treatment which addresses the pain but which is not too much treatment. Another problem with pain management is that pain is the body's natural way of communicating a problem. Pain is supposed to resolve as the body heals itself with time and pain management. Sometimes pain management covers a problem, and the patient might be less aware that they need treatment for a deeper problem (Consumer Showed, 2016).

Pain management is important for ongoing pain control, especially if the patient who suffer with long-term or chronic pain. After getting a pain assessment, your doctor can prescribe pain medicine, other pain treatments, or psychotherapy to help with pain relief (webmd, 2017).

Pain management can be simple or complex, depending on the cause of the pain. An example of pain that is typically less complex would be nerve root irritation from a herniated disc with pain radiating down the leg. This condition can often be alleviated with an epidural steroid injection and physical therapy. Sometimes, however, the pain does not go away. This can require a wide variety of skills and techniques to treat the pain. These skills and techniques include (Standiford Helm II,2017):

1. Interventional procedures
2. Medication management
3. Physical therapy or chiropractic therapy
4. Psychological counseling and support
5. Acupuncture and other alternative therapies; and
6. Referral to other medical specialists

All of these skills and services are necessary because pain can involve many aspects of a person's daily life. The treatment of pain is guided by the history of the pain, its intensity, duration, aggravating and relieving conditions, and structures involved in causing the pain. In order for a structure to cause pain, it must have a nerve supply, be susceptible to injury, and stimulation of the structure should cause pain. The concept behind most interventional procedures for treating pain is that there is a specific structure in the body with nerves of sensation that is generating the pain. Pain management has a role in identifying the precise source of the problem and isolating the optimal treatment (Standiford Helm II,2017).

When nurses feel they can no longer help the terminally ill recover, they begin to experience a deep sense of sadness, ambivalence, and helplessness. They do not know how to cope with the dilemma of providing palliative and curative care (Yam, Rossiter,, and Cheung, 2001). The bedside nurse who is with a child for a 12-hour shift is probably the best person to assess the effectiveness of the current pain medication regimen and other end-of-life needs. However, the nurse may report poor pain control or the need for a patient care conference, and the request may not even be considered. When nurse input is ignored, nurses may become angry, frustrated, and resentful about the care being provided to patients (Berry, and Ward, 1995).

2.3 End-Of-Life Care

In medicine, nursing and the allied health professions, end-of-life care (or EoLC) refers to health care, not only of patients in the final hours or days of their lives, but more broadly care of all those with a terminal illness or terminal condition that has become advanced, progressive and incurable. The purpose was to develop an end-of-life care (EoLC) policy for patients who are dying with an advanced life limiting illness and to develop practical procedural guidelines for limiting inappropriate therapeutic medical interventions and improve the quality of care of the dying within an ethical framework and through a professional and family/patient consensus process (Myatra et al., 2014).

End-of-life care requires a range of decisions, including questions of palliative care, patients' right to self-determination (of treatment, life), medical experimentation, the ethics and efficacy of extraordinary or hazardous medical interventions, and the ethics and efficacy even of continued routine medical interventions. In addition, end-of-life often touches upon rationing and the allocation of resources in hospitals and national medical systems. Such decisions informed both by technical, medical considerations, economic factors as well as bioethics. In addition, end-of-life treatments are subject to considerations of patient autonomy. "Ultimately, it is still up to patients and their families to determine when to pursue aggressive treatment or withdraw life support (Francis, and Lauren, 2011).

In most advanced countries, medical spending on those in the last twelve months of life makes up roughly 10% of total aggregate medical spending, and spending on those in the last three years of life can account for up to 25% (French et al., 2017).

EoLC Program was set up to improve the quality of care for people at the end of life. In particular, it aimed to help more people to live and die in the place of their choice. It also aimed to reduce the number of people who live in care homes being moved unnecessarily to hospital in the last weeks of their life. This was achieved by educating and training staff in end of life care (Fowler et al., 2006).

As children transition to end-of-life care, finding appropriate physician supports can sometimes prove challenging. For families facing the death of a child, the best transition is no transition at all. Ideally, end-of-life care would be provided by the physician that knows the child and family best – often their primary care provider (Morrison, 2013). Nurses can have a prominent role in end-of-life care. They should however have the appropriate knowledge and practice about Palliative Care (PC) in order to provide high quality of care at the end of life of for chronically sick patients. As it is recognized that nurses can have a prominent role in end-of-life care, it is important to assess their knowledge by identifying their knowledge gaps in order to develop education programs that address their learning needs. In fact, there is a need to constantly support and educate nurses in order to provide high quality palliative and end-of-life care (Maria et al., 2016).

The concept of palliative end-of-life care can be defined as active total care from a physical, mental, social and existential perspective, when an illness can no longer be cured. Through good symptom alleviation and optimized quality of life for the patient, as well as support for relatives during and after the time of illness, prerequisites for a good death are created. However, in the literature there is no consensus of what a good death connotes. Several studies showed the possibility for the patient to die in a way that is consistent with his/her wishes. Stein Hauser found six major components of a good death: symptom management, clear decision making, preparation for death, completion, contributing to others and affirmation of the whole person. According to Rinell-Hermansson and Ternestedt, the 6 S, that is symptom control, self-determination, social relations, self-image, synthesis and surrender, can be used as key-words in nursing documentation as well as in follow up sessions after death with staff and relatives, creating and evaluating the quality in the dying process. These demonstrate the importance of a great awareness of the patient’s total situation in end-of-life (Wallerstedt, and Andershed, 2007).

While the death of a patient is an event that all nurses will face, historically, the preregistration curriculum has failed to directly address this issue (Quint 1967, Kiger 1994). Quint’s (1967) landmark study on nurse education highlighted considerable inadequacies and subsequently influenced the way in which death and dying was taught in nursing schools. Not until the birth of the hospice movement did death education adopt a more holistic approach. Nonetheless, despite an increasing in awareness and inclusion of death education in pre-registration curricula (Dickinson et al., 2008), there is evidence to suggest persistent shortcomings in the nursing profession’s ability to meet the needs of dying patients. Allchin (2006) thus comments that nurse educators for more than thirty years had been calling for a greater emphasis in nurse training on end of life care, with this lack of education reflected in the quality of end of life care provided to patients (Brajtman et al 2009). The overall purpose of end of life care is a ‘good death’ for individuals whose condition cannot be cured (Mercer and Feeney 2009). The origins of a ‘good death’ ideology lie within the hospice philosophy that has become embedded in contemporary Western palliative care and end of life education (Bradbury 2000, Costello 2006).

Emphasis on a holistic approach, that values the whole person in individual context, was central to palliative care principles that influence understandings of ‘good death’. Although symptom management has come to be seen as an important component of a ‘good death’, the evidence suggests that communication skills are an important factor in judging the quality of care received (Woods et al 2000, Johnston and Smith 2006) with modules on communication skills featuring heavily within end of life nurse education (Dickinson et al 2008). (Cavaye, and Watts, 2012).

2.4 Hospice Care

Hospice care is a type of care and philosophy of care that focuses on the palliation of a chronically ill, terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. In Western society, the concept of hospice evolved in Europe since the 11th century. Then, and for centuries thereafter in Roman Catholic tradition, hospices were places of hospitality for the sick, wounded, or dying, as well as those for travelers and pilgrims. The modern concept of hospice included palliative care for the incurably ill given in such institutions as hospitals or nursing homes, but also care provided to those who would rather spend their last months and days of life in their own homes (Hospice Promise, 2018).

Hospice care focused on improving the quality of life for persons and their families faced with a life-limiting illness. The primary goals of hospice care were to provide comfort, relieve physical, emotional, and spiritual suffering, and promote the dignity of terminally ill persons. Hospice care neither prolongs nor hastens the dying process. As such, it is palliative not curative. Hospice care philosophy or approach to care rather than a place. Care may be provided in a person's home, nursing home, hospital, or independent facility devoted to end-of-life care. Hospice care is holistic: Hospice treats the whole person, not just the disease. It focuses on the needs of both the patient and the family. The health care teams attend practical needs such as insurance coverage, transportation, and assistance with bathing in addition to emotional and spiritual needs such as caregiver stress, grief, and fear of dying. Care is provided by an interdisciplinary team including the physician, psychologist, nurse, social worker, chaplain, pharmacist, nursing assistant, volunteers, nutritionist, and physical therapist. (Hospice Promise, 2018).

Hospice care is a specialized form of palliative care customarily provided during the last few months of a person's life. Persons with a life-limiting disease may receive palliative care early on in the course of their illness to relieve pain and other physical symptoms and to assist them in coping with how the illness impacts their daily living and family. The goals of both palliative care and hospice care are to relieve suffering and to improve quality of life. Two primary differences exist between hospice care and home health nursing. First, any patient with a skilled medical care should be qualified to receive home health nursing care. The patient may be recuperating from heart surgery or require intravenous medication for an infection from which they are expected to recover. Hospice care, on the other hand, is limited to persons with a terminal illness, usually with a life expectancy of six months or less, and with a focus on palliation not cure. Second, whereas persons in home health care receive visits primarily from a nurse (additional services such as physical or occupational therapy are sometimes ordered), persons in hospice care receive the services of an entire interdisciplinary team whose area of expertise is end-of-life care (Contro et al., 2004).

It has long been recognized that the majority of people die in acute hospital wards rather than home or hospices. This has led to a number of initiatives designed to transfer best practice for dying patients from hospices to hospitals. Despite these efforts, nurses are working in hospitals and community settings without knowledge of how best to assist patients and families facing the end of life (Burt et al., 2008). Hence, partners and family cares may be excluded from end of life decisions and patients may not be enabled to return home to die if that is their wish. In addition, staffs are not taught to recognize that death does not always represent a failure of the healthcare system nor, indeed, are they provided with ongoing training in this area (Department of Health, 2008) (Cavaye, and Watts, 2012).

2.5 Palliative care

The word "palliative" is derived from the Greek language. It is translated as "to cloak". In the care of the dying, the interventions are meant to prevent the experience of pain and other agonizing symptoms. The National Hospice and Palliative Care Organization (NHCPO) in the USA define palliative care as "treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life." (Connor, 2009). Palliative care can be defined 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 (WHO, 2014). Palliative care is the active, total care of patients and their families by a multidisciplinary team; at a time when the patient's disease is no longer responsive to curative treatment and life expectancy is relatively short (Twycross, 2003). Lynn, and Adamson's model (2003) indicated that the principles of palliative care were already applicable in an early stage of the disease and can go together with therapies that are initially aimed at the prolongation of life. A system approach is important; as the palliative process progresses the relief of symptoms will get more attention; the family care became more intensive (Ayed et al., 2015). Palliative care is not limited to cancer or even to the terminal stages of illness; it can last for years, and can be applied to any life-threatening disease, though it is most often associated with cancer. Palliative care is not an alternative to other care but is a complementary and essential component of total patient care (Costello, 2004). Palliative care was not restricted to a certain setting but takes place in different environments, both at home, in hospitals, in nursing and old-people's homes, in psychiatry and in hospices. In Europe palliative care was considered as general care, which means that every professional health-care provider must be able to provide care for palliative patients in different healthcare services. General care promoted the accessibility and availability of palliative care (Ahmedzai et al., 2004).

Palliative care philosophy evolved from the hospice philosophy to meet the gaps in care for seriously ill and dying patients. it aimed that pediatric palliative care should best intersect with the aims of curing and healing, and this approach should be instituted when diagnosis, intervention, and treatment are not limited to a disease process, but rather became instrumental for improving the quality of life, maintaining the dignity, and ameliorating the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community. Like hospice care, palliative care recognized people of all ages die and that caregivers' attention should be focused on relieving patients' pain and suffering. Furthermore, palliative care considered the patient and family as a unique entity whose members require care both before and after death. Palliative care recognized the role of the physician as one key member of an interdisciplinary team assisting patients and families with the myriad physical, social, psychological, and spiritual needed that come into play when a child has a life-threatening illness (Himelstein et al., 2004).

Palliative care is an essential part of the nursing care that can be delivered at different levels of complexity (De Vlieger et al., 2004). Palliative care clinical nurse specialists played an important role in specialist palliative care. They spent time with patients and their families, helping them come to terms with an array of complex emotional and practical problems, facilitating communication, giving information and advice about treatments and also offering expertise in controlling pain and other distressing symptoms. These nurses are equipped with specialist skills to assess the complex palliative care needs of patients referred to the (Ahmedzai et al., 2004). The positive impact of palliative care is well documented, including improving patient pain symptoms and patient satisfaction with care (Lautrette et al., 2007) as well as decreasing hospital costs. Furthermore, a recent study showed that palliative care provided from the time of diagnosis for lung cancer patients may increase patient survival in addition to benefitting mood and quality of life (Ferris et al., 2009).

Palliative care for elders differs from what is usually appropriate in younger adults because of the nature and duration of chronic illness during old age. The prototypical example of a palliative care patient is that of a 55-year-old mother of two with advanced ovarian cancer. Care for this patient would include chemotherapy until it no longer meets the patient's goals of care; treating her symptoms (e.g., nausea, pain, fatigue); addressing her psychological and spiritual concerns; supporting her partner; and helping to arrange for care of her children after her death. The majority of this patient's care occurred at home (with or without hospice) or in the hospital, and the period of functional debility is brief (months). In reality, a frail 88-year-old widowed woman with advanced heart failure, diabetes mellitus, osteoarthritis, mild cognitive impairment, and frailty typifies the most common example of a patient requiring palliative care. Palliative care for this patient involved treating the primary disease process (advanced heart failure); managing her multiple chronic medical conditions and comorbidities (diabetes mellitus, arthritis) and geriatric syndromes (cognitive impairment, frailty); assessing and treating the physical and psychological symptom distress associated with all of these medical issues; and establishing goals of care and treatment plans in the setting of an unpredictable prognosis.

Additionally, the needs of her caregivers are also different from those of the caregiver of the younger patient. Individuals caring for geriatric patients were often adult children with their own families, work responsibilities, and medical conditions. These roles must be balanced with the months to years of personal care that they will provide to their aging parent. Finally, because older adults often make multiple transitions across care settings (home, hospital, rehabilitation, long-term care), especially in the last months of life, palliative care programs for older adults must assure that care plans and patient goals are maintained from one setting to another. Thus, palliative care for the elderly is centered on the identification and amelioration of functional and cognitive impairment; the development of frailty leading to dependence on caregivers; symptom, emotional, and spiritual distress; and bereavement needs of adult children and elderly partners (Morrison, 2013).

Palliative care is appropriate for children with a wide range of conditions, even when cure remains a distinct possibility. The American Academy of Pediatrics has supported concepts of palliative care, stating that “the components of palliative care should be offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.” Palliative care should be accessible in any setting, including home, hospital, and school (AAP, 2000).

2.6 Pediatric Palliative Care

Pediatrics is the branch of medicine that involves the medical care of infants, children, and adolescents. The American Academy of Pediatrics recommended people being under pediatric care up to the age of 21 (AAP, 2017). The responsibility of pediatrics may therefore begin during pregnancy and usually terminates by 21 years of age (Jennison et al., 1972).

A pediatrician is a child's doctor who provides:

1. Preventive health maintenance for healthy children.
2. Medical care for children who have short-term or long-term sickness.
3. Pediatricians manage the physical, mental and emotional well-being of their patients, in every stage of development.

Generally, pediatricians focus on babies, children, adolescents, and young adults from birth to age 21 years to:

1. Reduce infant and child mortality
2. Control infectious disease
3. Foster healthy lifestyles
4. Ease the difficulties of children and adolescents with chronic conditions.

But, pediatricians are concerned with more than physical well-being. They also are involved with the prevention, early detection, and management of other problems, including behavioral difficulties, developmental disorders, functional problems, social stresses and depression or anxiety disorders (AAP, (2017); UMMC ,(2017).

Pediatric palliative care was first introduced by the World Health Organization (WHO) in 1990 and is a relatively new specialty developed in response to inadequacies in treatment for children and their families facing life-limiting and life-threatening illnesses. Palliative care is a comprehensive approach that addresses physical, emotional, social and spiritual elements, with a focus on coordination of care, quality of life for the child and support for the family beginning at diagnosis and continuing throughout treatment, death and bereavement (Institute of Medicine (IOM) 2003, World Health Organization (WHO) 2004, National Hospice and Palliative Care Organization (NHPCO) (2008) (Williams-Reade et al., 2015).

Palliative care seeks to enhance quality of life in the face of an ultimately terminal condition. Palliative treatments focus on the relief of symptoms (pain, dyspnea) and conditions (loneliness) that cause distress and detract from the child’s enjoyment of life. It also seeks to ensure that bereaved families are able to remain functional and intact (AAP, 2000). Palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of children and their families living with life-threatening or terminal conditions (Frager,1996). The goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient. The World Health Organization (WHO) defines palliative care for children as (WHO, 1998):

The active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

Effective PC 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.

This broad definition emphasized the prompt management of symptoms; it included the patients, family, and healthcare providers in the caring process; it took into consideration the physical, emotional, and spiritual aspects of care; and it went beyond the period of care to include counseling and support of the bereaved.

The American Academy of Pediatrics called for the development of clinical policies and minimum standards that promote the welfare of infants and children living with life-threatening or terminal conditions and their families, with the goal of providing equitable and effective support for curative, life-prolonging, and palliative care (Cassel, and Foley, 1999). The following principles serve as the foundation for an integrated model of palliative care (AAP, 2000):

1. Respect for the Dignity of Patients and Families.
2. Access to Competent and Compassionate Palliative Care.
3. Support for the Caregivers.
4. Improved Professional and Social Support for Pediatric Palliative Care.
5. Continued Improvement of Pediatric Palliative Care through Research and Education.

Pain is a major symptom in pediatric palliative care, both in children with cancer and those with non-malignant life-limiting or life-threatening conditions. Children with life-limiting conditions suffer from many distressing symptoms. Studies found the most common symptoms to be pain, lack of energy, fatigue, and dyspnea; other symptoms include nausea, lack of appetite, drowsiness, cough, and other psychological symptoms like sadness, nervousness, worrying, and irritability.

Wolfe et al., (2000) reported that 89% of the children experienced a great deal of suffering from at least one symptom, and 51% suffered from three or more symptoms. Fatigue is another common symptom in children with life-limiting conditions especially cancer and is the least successfully treated. Fatigue was another common symptom in children with life-limiting conditions especially cancer and was the least successfully treated. Fatigue was prevalent in almost 100% of children, as conveyed by parents (Wolfe et al., 2000), and in more than 75% in a study assessing symptoms of dying children (Drake et al., 2003).

As long as symptoms are not assessed and measured adequately, children will continue to suffer needlessly. Measurement of symptoms is considered as one aspect to evaluate the overall quality of life and quality of palliative care. Several validated tools are available in the literature to measure the prevalence of symptoms in the pediatric population. The most commonly used comprehensive tool is the Memorial Symptom

Assessment Scale (MSAS) that measures the frequency, severity, and distress level of 30 symptoms (Collins et al., 2002); another tool was the Global Distress Index which combines the ten most prevalent and distressing physical and psychological symptoms. Other tools available are more symptom-specific like the pain tools (Visual Analogue Scale, Numeric Rating Scale, and the Faces Scale) (Abu-Saad, 2008).

Management of symptoms should follow an aggressive approach to improve symptom control and decrease symptom burden. The following core standards for symptom management are provided (Graig et al., 2007).

1. Every child should have access to professional pharmacological, psychological and physical management of pain and other symptoms, 24 hours a day, 365 days a year.
2. Every child must have their symptoms assessed so that they can receive an appropriate treatment to achieve an acceptable level of comfort.
3. Psychological, social and spiritual symptoms must be addressed, as well as physical ones.
4. Symptom management must be accomplished through means acceptable to the patient, family and professionals.

2.7 Pediatric Nurses; Knowledge, Attitudes and Practices

Palliative care is a dynamic discipline with a multidisciplinary nature that requires interdisciplinary group work on the part of doctors, nurses, social workers, psychologists, nutritionists and rehabilitation professionals; however, the amount of support from each of the disciplines varies from one institution to another. In order to be able to provide for the needs of the patients and their families, it was necessary for palliative care to change its current disease-oriented approach to a patient oriented one. The patient-oriented approach required a greater focus on care and a greater coordination among specialists from different disciplines as well as a greater availability of nurses and doctors specialized in palliative care (Grant et al., 2009).

In the multidisciplinary palliative care team, nurses were often the first professional care providers that assess and identify the pain and suffering of the patients. In addition, nurses spent the longest hours with the patients and played a major role in making decisions for them (Razban et al., 2013).

Palliative care cannot be effective without a proper nurse-patient relationship. Researchers believe that the nurse-patient relationship is the key element in providing proper palliative care. This relationship can improve various aspects of palliative care, including its physical, emotional, psychological and spiritual aspects. It can also facilitate the patient's coming to terms with his conditions, reduce his pain and ultimately create a better end-of-life experience for him (Sajjadi et al., 2015).

A high level of pain is expected after surgery whereas inadequate pain management practices are reported. For children, in particular who cannot speak when they are in pain, inadequate pain management is deleterious and can lead to a number of post-operative complications. Therefore, it must be relieved completely (Rao, 2006). For effective postoperative pain management in children, a strong clinical knowledge, attitude and skills are essential for pediatric nurses (Vincent, 2005).

Nurses find it difficult and emotionally heavy to deliver palliative care to patients and often do not feel competent enough (White et al., 2004). Nurses as well as other healthcare workers often feel not well prepared for their task in palliative care and are much in need of more expertise in the field of pain and symptom management, communication and dealing with ethical dilemmas. They would moreover like to be supported in the coordination of the care when many different care providers are involved (Wallerstedt, and Andershed, 2007; Osse et al., 2006). It can be argued that nursing and palliative care are natural partners in clinical practice and that the knowledge and skills required in this area are applicable to all nurses. People die in many environments and all have a right to supportive and palliative care, regardless of diagnosis or circumstances (the National Comprehensive Cancer Network (NICE), 2004) (Ayed et al., 2015).

Nurses play a major role in providing training and care to patients. The training provided by nurses to patients in end-of life stages can positively affect their awareness and attitude and reduce their problems to a certain extent (Nagamatsu et al., 2014). Providing palliative care to the pediatric population is very challenging; societies in general do not expect children to die and believe that medicine can cure all diseases. In addition, poor communication and feelings of guilt force parent and caregivers to choose all life-prolonging therapies to avoid being accused of not caring enough for their child; determining the best interest of the child is usually very difficult for families and healthcare professionals. Lack of education and awareness regarding palliative care services existed among the public and among healthcare professionals; very few physicians and nurses were highly experienced in the care of dying children and their families. There was a misperception among the public, administrators, and healthcare professionals that palliative care should be offered only when all other curative efforts have been extensively used (Levetown et al., 2001).

Studies conducted on palliative care in recent years have largely demonstrated the problems and barriers against nursing education in palliative care. A general challenge in nursing education was the absence of appropriate educational models and operational plans (Moonaghi et al., 2013).

Dangel (2002) reported that in Europe several obstacles to develop palliative care programs exist: lack of funds and reimbursement, lack of awareness, lack of cooperation between hospice programs and pediatricians, physicians' attitudes, lack of staff, lack of governmental support and policies, and lack of education.

A study conducted in the Netherlands among general practitioners described the lack of knowledge and skills in palliative care as barriers to daily practice. A survey conducted in Scotland on public awareness of palliative care found the majority of respondents to have some knowledge of palliative care, with 32% reporting no knowledge and only 3% to have high levels of knowledge of palliative care (Scottish Partnership for Palliative Care, 2003). Healthcare professionals have consistently reported the need for further education and training in palliative care. The European Association for Palliative Care (EAPC) recommended that all professionals and volunteers working in pediatric palliative care should receive comprehensive training and support; in addition, palliative care training must be a core part of the curriculum that should be developed by each country (Ahmedzai et al., 2004).

A general challenge in nursing education is the absence of appropriate educational models and operational plans. The lack of educational programs enabling health professionals to provide these services is proposed as a major challenge. To ensure the optimal implementation of palliative care, health care providers should have a proper understanding of palliative care, which requires knowledge and awareness. Studies indicate the poor knowledge of healthcare providers about palliative care and its underlying philosophy, symptom management and of the means of providing this type of care; only a few groups are engaged in providing palliative care to cancer patients. Nurses receive only a general education at the undergraduate level and their promotion in their job demands passing additional courses (Sajjadi et al., 2015).

It is important to develop adequate programs in the field of palliative care for nurses at all levels, as these disciplines are seen as core disciplines (Ahmedzai et al., 2004). The nurses make up a large part of the healthcare profession, yet they are falling behind on instituting palliative care within the curriculum. This is impressive considering how prevalent nurses are in initiating patient care and being the primary caregiver to those hospitalized. When entering the healthcare field, death of a patient is unavoidable and became part of the job as a nurse. It is important to integrate palliative care education within the Bachelor of Science in Nursing (BSN) degree to better prepare new graduates for the inevitable care of a terminally ill patient. Nursing students and new graduate nurses are not adequately prepared for caring for this specific population. The challenge with integrating palliative care education into nursing curricula were time constraints and the volume of materials necessary to prepare BSN nurses for the complexities of caring for terminally ill patients and their families (Ayed et al., 2015).

Nursing schools have not adequately incorporated palliative care into the curriculum to increase awareness of palliative care content and skills asserted that students are lacking in knowledge on palliative care. Students cannot be expected to be experts in any capacity due to lack of experience in the clinical area; however, schools and hospitals are holding students and new graduates accountable for this material and expect an adequate competency level despite lack of training and teaching on the subject (Sadhu.et al., 2010). In order to better prepare students to care for dying individuals, implementation of palliative care experiences within the nursing curriculum is critical (Brajtman et al 2009).

Many nurses have family and language limitations for participation in training programs held by sponsor institutions. Using on-line programs is also not easily possible due to the heavy workloads and/or the lack of access to computers and internet at home. Palliative care has been neglected as an independent discipline in school curricula, which is potentially due to the experts' own lack of knowledge about the importance of the issue, the lack of opportunities for providing palliative care and the lack of teamwork in healthcare (Sajjadi et al., 2015).

Providing good palliative care requires an inner commitment from the nurses who are involved, that depends on how these nurses view death and persons who are dying. Nurses' view toward caring for dying person could be described by their attitude (Iranmanesh et al., 2010). Attitudes are formed as a result of evaluating a particular entity with some degree of favor or disfavor and are expected to change over the time by experience. These attitudes are attached to human emotions, and to actions (Peters et al., 2013). The care of death and dying patients is a challenge for nurses who have raised a special interest in the recent years (Roman et al., 2001).

Nurses are frequently exposed to the care of death and dying. This experience often raises the anxiety and undesired attitudes that reflect on the quality of patient's care (Peters et al., 2013).

Nurses' attitude toward palliative care affects their care behavior toward patients in end-of-life stages. Nurses with a negative attitude toward death and dying tend to avoid direct contact with a dying patient and have no desire to tell the truth to the patient or discuss the subjects of disease and death. Nurses' attitude toward death and dying affects the care they provide to dying patients and their families. Although their religious beliefs make them consider caring for dying patients a worthwhile and rewarding job (Sajjadi et al., 2015).

A study used a convenience sample of 403 nurses from a private hospital and the Visiting Nurse Association Hospice Division, (Rooda et al., 1999) found that nurses with greater fear of death exhibit fewer positive attitudes regarding caring for dying patients. In a study, (Dunn et al., 2005) found that nurses with greater exposure to dying patients reported more positive attitudes. Understanding nurses' attitudes in a specific situation can therefore predict the quality of EOL care that patients may receive (Frommelt, 1991). A study of 410 pediatric nurses, (Feudtner et al., 2007), concluded that nurses with more years in practice, more hours of palliative care education, and higher hope scores were more comfortable caring for dying children. Similar results were also obtained in a comprehensive cancer center in New York, where, (Lange et al.,2008), found that nursing experience and age were the variables most likely to predict nurses' attitudes toward death and caring for dying patients.

The lack of a proper job description and the mere performance of routine tasks have made people view nurses as only doctors' assistants and regard doctors as the main member of the medical team in charge of providing care. This attitude has lowered the social status of nursing and has killed nurses' motivation for providing services in a way that is becoming of their profession; as a result, participation in ongoing training courses and workshops does not affect the nurses' performance to a great degree (Sajjadi et al., 2015).

In palliative care, research studies have indicated that, to provide quality end of life care and establish meaningful and supportive relationships with patients and their families, healthcare providers must be comfortable with death and dying. Communication with patients and their families regarding all aspects of their care, in particular end of life care, is critical (Abu Hasheesh et al., 2013).

One study conducted in Iran showed that establishing an effective nurse-patient relationship is the main pillar of palliative care in patients with cancer. The study also showed the "human touch" to be the main experience of nurses and patients with cancer, which is expressed under two subthemes, including "total acceptance" and "psychological support" (Borimnejad et al., 2014). Another study conducted in Iran showed that establishing a close care relationship with the cancer patient and his relatives is the basis of care. A reflective approach should be adopted in training oncology department nurses so as to help them develop their nursing care skills (Iranmanesh et al., 2010).

Another challenge and at times an obstacle facing the provision of adequate palliative care is conducting research in this area. Research in pediatric palliative care that will eventually provide the evidence-base leading to improvements in care and education is still lacking. Adequate funding for research must be available to ensure the delivery of best practices. The vulnerability of this population (children and parents) and the ensuing burdens should be taken into consideration when designing such studies (Tomlinson et al., 2007).

Further research is needed to identify and implement ways to decrease highly rated obstacles and to continue to support highly rated supportive behaviors. Pediatric palliative care is still in its infancy. Quality end-of-life care is still not being implemented or being documented in most hospitals (Brandon, 2007).

2.8 The Palliative Care Quality Network (PCQN)

The Palliative Care Quality Network (PCQN) is a large consortium of palliative care (PC) teams in the United States who are collecting standardized data about the practice of PC. It aims to describe patients referred to inpatient PC, care provided by PC teams, and clinical outcomes. Seventy-one PCQN members entered data on 48,290 patient encounters between January 3, 2012 and June 30, 2016. The results were patients referred to PC were an average of 72 years old (median=74) and were significantly debilitated (mean palliative performance scale=35.2). The most common diagnosis leading to PC consult was cancer (32.8%). Common reasons for referral to PC were goals of care discussions (73.1%), followed by pain management (20.2%), and providing support for patient/family (20.0%). Patients were referred to PC an average of 4.7 days (median=2) after hospital admission and were followed by the PC team for an average of 5.0 days (median=3.0). Disciplines involved in PC consultations included physician (50.5%), social worker (36.5%), registered nurse (33.4%), and chaplain (31.8%). Of patients with moderate to severe symptoms, 68.5% reported improved pain from the 1 st to 2 nd PC assessment, 78.4% reported improved nausea, 65.9% reported improved dyspnea, and 65.7% reported improved anxiety. A surrogate decision maker was identified for 95.2% of patients seen by PC. On average, patients had 1.2 family meetings with the PC team (median=1). Forty-four percent of patients had their code status clarified, 12.2% had a POLST form completed, and 3.1% completed an advanced directive. Three quarters of patients were discharged alive, with home being the most common discharge location (48.2%). Hospice services were arranged for 38.0% of patients. This multicenter dataset allows us to understand the services provided by inpatient PC teams, and the impact of that work. These data can be used to define best practices and drive quality improvement in PC (Aldridge et al., .2016).

2.9 Frommelt Attitudes Toward Care of The Dying Scale (FATCOD)

The Frommelt Attitudes toward Care of the Dying (FATCOD) Scale is a 30-item scale designed to measure participants’ attitudes toward providing care to dying patients. While two-thirds of the statements address nurses’ attitudes toward the dying patient, the other third address nurses’ attitudes toward the patient’s family (Frommelt, 1991).

The Frommelt Attitude toward Care of the Dying (FATCOD) scale: Is a 30-item tool using a five-point Likert scale to indicate respondents' attitudes toward caring for dying patients. The scale consists of an equal number of positively and negatively worded statements with response options of strongly disagree, disagree, uncertain, agree, and strongly agree. Positive items are scored one (strongly disagree) to five (strongly agree). Scores are reversed for negative items. Possible scores can range from 30-150. A higher score showed a more positive attitude toward caring for dying patients (Abu Hasheesh et al., 2013).

2.10 The palliative care quiz for nursing (PCQN)

The Palliative Care Quiz for Nurses (PCQN) is useful to evaluate basic knowledge about palliative care. The PCQN was a 20-item true, false and 'I don't know' test of knowledge that is easily administered and has utility for assessing knowledge, stimulating discussion and identifying misconceptions about palliative care nursing. The development of the palliative care quiz for nursing (PCQN) entailed the convening of an advisory committee, a wide process of consultation, the development of a conceptual framework, determination of format, generating of items and pre-testing, piloting and further testing of the quiz. It appears that the PCQN is useful for identifying misconceptions within groups and that the rank order of frequency with which these errors are made differs among groups, depending on level of education. The effective measurement of knowledge is an important component of both nursing education and nursing practice. Such measurement can serve a variety of purposes including the assessment of learning needs and evaluation of programs and services. The process used in the development of the PCQN is participatory, consultative and comprehensive in nature and involved those most knowledgeable about palliative care nursing at all phases of development the palliative care quiz for nursing appears to be a promising tool with utility for assessing knowledge, stimulating discussion and identifying misconceptions. The quiz can be used for assessing learning needs and may be useful as a teaching tool and for contributing to the evaluation of educational programs related to the provision of palliative care. The development of the palliative care quiz for nursing helps to fill the gap in instrumentation available for teaching and research initiatives aimed at improving the quality of education received by health care providers and ultimately the quality of palliative care received by those who are dying and their families (Ross et al.,1996).

The Palliative Care Quiz for Nursing (PQCN) assesses three aspects of palliative care: philosophy and principles (4 items), control of pain and other symptoms (13 items) and psychosocial aspects (3 items). These 20 items refer to a knowledge that is applicable in clinical settings, and it could be submitted to both students and professional nurses (Ross et al.,1996).

According to various research studies, the different versions of PCQN have shown to be a useful instrument to measure nurses level of knowledge and also to identify misconceptions in the field of palliative care (Adriaansen, and van Achterberg, 2004).

Chapter Three

Methodology (Materials and Methods):

3.1. Study Design

A descriptive cross-sectional study design was used to answer the proposed research questions. Demographic characteristics, attitude and practice in pediatric nursing, and barriers have been measured simultaneously from the specified group of pediatric Nurses Practitioners using a self-administered questionnaire.

3.2. Study Setting

The data was collected over a period of 4 months, extending from Jul 2017 to august 2017. Quantitative data will be obtained from nurses in the PW and PICU and P.O.H, Hematology, Oncology at 12 private hospitals in west bank of Palestine. These hospitals include: Al Zakat hospital, Alengele Hospital, ALNajah University Hospital, Al Ittihad Hospital, Specialist Hospital Nablus, Arab Specialist Hospital, Arab Care, Augest Victoria hospital and Almakassed Hospital, Red Crescent Hospital, Al Ahli Hospital, Caritas Hospital.

3.3. Study Population

The population consisted of all nurses working in Pediatric ward (PW), Pediatric Intensive Care Unit (PICU), POH, Hematology, Oncology and Clinical Outpatient Services at the private hospitals.

3.4. Sample Size

To achieve confidence interval of 95% and standard error of 5%, the single proportion equation was used to calculate the sample size. Based on prior similar studies conducted on Palliative care for children with cancer (Waldman & Wolfe, 2013), an expected effect size of 30% was expected in this study. The power of detecting a difference between groups was set at 0.80. The present study required a total of 236 nurses in 12 private hospitals to detect a difference on Palliative care among groups at $\alpha = 0.05$

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3.5. Sampling Technique

Stratified sampling technique was used to select the participants. Based on the lists of the employees' names that will be obtained from each participated hospital, the required sample size from each hospital will be taken in proportion to the size of employees (total number of nurses in all departments in each hospital). Then the required number of nurses from each hospital will be distributed proportionately between the departments depending on the size of each department (number of nurses in each department), then the required number from each department will be drawn by simple random sampling without replacement.

3.6. Sampling Frame

A list of names of the nurses working in the pediatric units at private hospitals was obtained from the human resources. The sampling frame for the first part will be based on inclusion and exclusion criteria, as follows:

- Inclusion criteria: nurses in PW, PICU and normal POH, Hematology and Oncology

- Exclusion criteria: nurses who are in holiday, retirement, other department, family with healthy or sick pediatric.

3.7. Dependent Variables

The dependent variable was the attitude and practice with barriers of PW, as determined by the overall attitude and practice and barriers score in appendix 2.

3.8. Independent Variables

Palliative care services sub scores. The main independent variable, the overall palliative care services offered in pediatric world in all departments. Additional independent variables obtained from the demographic section were controlled for. These were : Gender, Age, and Professional degree status, years of experience in PICU, PW POH AND HEMATOLOGY AND ONCOLOGY, CLINCAL OUT PATIENT, and Geographic region, how many Pediatric died on the unit in the past 12 months, how many pediatric were discharged to home hospice in the past 12 months, University affiliation.

3.9. Administration of the Instrument

Global questionnaire was used to collect data about attitude and practice and barriers that effect on caring of child life threatening condition and their family. The t-test and F-test were computed to examine the relationships between nurses' attitudes toward care of dying and death and demographic factors. The study utilized a demographic questionnaire, the nursing Palliative Care Quality Network (PCQN), and from melt attitudes toward care of the dying scale (FATCOD). Depend in appendix (1), (2) and (3) find domain and type of question in each section.

A pilot study was conducted with twenty nurses to determine the clarity of questions, effectiveness of instructions, completeness of response sets, time required to complete the questionnaire and success of data collection technique. Pilot subjects were asked to comment on the applicability and appropriateness (validity) of the questionnaire. All questions were answered no clarity of questions was required. The researchers determined that it would take twenty (20-30) minutes to complete the questionnaire.

3.10. Data Analysis

Data from all eligible participants was entered into the SPSS statistical software program, where it formed a master database. Mean scores and standard deviations were calculated for overall scores and sub scores from each section. A descriptive analysis of each section was made.

The analysis then focused on the relationship between palliative care services available and nursing satisfaction with work and work culture in terms of the WQI score. The P-value ≤0.05 will be set as a criterion of statistical significance.

3.11 Limitations of the Study

1 - Difficulty of movement and transportation for long distances, especially because the study on all areas of the West Bank

2. The government refused to allow the research, which made the available sample few.

3 - Lack of a large number of specialized hospitals for the care of children.

3.12. Ethical Consideration

- Explain the purpose of my research to medical healthy team and show the important of the study in our country to meet need patient and their family.
- Take permission from nurses to full my questioner without any pressure.
- To provide private hospital final result of my research.

Chapter Four:

Results

4.1 Introduction

This chapter included a presentation of the results of the study, that were obtained through answers of the study questions and review of the results of the questionnaire, and analysis of its items, in order to describe the attitudes and practices of pediatric nurses regarding the care of children with life-threatening conditions and their families and assess the barriers that impede nurses' ability to provide care for these patients and their families, within the study variables (Gender, Age, Education, Years of experience, Nurses' position, Name of children suite, Number of pediatric deaths during the last year and Number of admitted children during the last year). Statistical analyzes of the data were carried out using the SPSS program to reach the results of the study which will be presented and analyzed in this chapter.

4.2 Socio-Demographic Characteristics of Sample Study

A descriptive, quantitative design was utilized for conducting the current study to accomplish its purpose. The study population was consisted of all nurses responsible for pediatric care. The study covered a convenience sample of 236 nurses involved with the pediatric care in 12 private hospitals in West Bank. All subjects agreed to participate in the study after being informed about the goals of the research. A descriptive quantitative design was utilized to accomplish the purpose of this study.

The nurses' attitudes toward caring of children living with life-threatening conditions and their families were measured using the (FATCOD) scale. The t-test and ANOVA-test were computed to examine the relationships between nurses' attitudes toward care of dying and death and demographic factors. The Socio-demographic Characteristics of the study sample were shown in (Table 4.1). From this table it can be noticed that most of the study sample were females (Figure 4.1a).

This is due to Arab customs and traditions, where it is preferred to employ female nurses to work in the children's ward, because many of mothers exist there with their children. Also, about 75% of the study sample were within age of 20 to 29 (Figure 4.1b), and most of them have BSN degree (Figure 4.1c) with up to 5 years of experience (Table 4.1).

Most of the sample of study was composed of staff nurses (55.1%) and practical nurses (30.5%) and most of them work in pediatric ward (Table 4.1).

As shown in (Table 4.1) about 62.3% of the participants reported that more than 40 cases had been admitted to the pediatric ward in the last year, and 78.4% of them reported that deaths during that year ranged from 1 - 20 deaths.

Table 4.1: Socio-demographic Characteristics

Characteristics		Frequency	Percentage
Gender	Male	74	31.4%
	Female	162	68.6%
Age	20 – 24	102	43.2%
	25- 29	74	31.4%
	30- 34	33	14.0%
	35- 39	19	8.1%
	40 and above	8	3.4%
Education	Diploma	76	32.2%
	BSN	138	58.5%
	MSN	22	9.3%
Years of experience	Less than 2 years	63	22.5%
	2 – 5 years	103	43.6%
	6-10 years	46	19.5%
	11- 20 years	30	12.7%
	More than 20 years	4	1.7%
Nurses' positions	Head nurse	18	7.6%
	assistant head nurse	16	6.8%
	staff nurse	130	55.1%
	practical nurse	72	30.5%
Name of children's suite	PW	139	58.9%
	PICU	50	21.2%
	pediatric cardiology	20	8.5%
	pediatric cardiology	24	10.2%
	pediatric oncology	3	1.3%
Number of pediatric deaths during the last year	1- 20	185	78.4%
	21-40	33	14.0%
	More than 40	18	7.6%
Number of admitted children during the last year	1 – 20	50	21.2%
	21 – 40	39	16.5%
	More than 40	147	62.3%

4.2 Inferential Hypothesis Concerned with Knowledge and Attitude of Pediatric Nurses Toward Child with A Life-Threatening Condition.

Table 4.2 indicated that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey according to gender in all subscale areas, but not in the area of relief of pain and other Symptoms where (p=0.030).

Table 4.2: The pediatric nurses' knowledge and attitude survey sub - scores according to Gender (independent t Test)

Variables	Gender	Mean	*t* statistics (df)	P-value
Holistic Care of the Child	Male (n=74)	11.08 (2.5)	-0.53(234)	0.600
	Female (n=162)	11.27 (2.6)		
Support of the Family Unit	Male (n=74)	16.99 (2.8)	-1.52 (234)	0.129
	Female (n=162)	17.66 (3.3)		
Involvement of Child and Family in communication … etc.	Male (n=74)	14.64 (2.9)	-0.28(234)	0.780
	Female (n=162)	14.75 (3.3)		
Relief of Pain and Other Symptoms	Male (n=74)	19.32 (2.5)	2.19(234)	0.030
	Female (n=162)	18.62 (2.1)		
Continuity of Care	Male (n=74)	10.35 (2.5)	0.19(234)	0.849
	Female (n=162)	10.28 (2.5)		
Grief and Bereavement Support	Male (n=74)	21.84 (2.6)	-1.14(234)	0.257
	Female (n=162)	22.25 (2.6)		

Table 4.3 points out that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey according to employment status in all subscale areas.

Table 4.3: The pediatric nurses' knowledge and attitude survey scores according to employment status (independent t Test)

Variables	Employment status	Mean	*t* statistics (df)	P-value
Holistic Care of the Child	Full-time (n=217)	11.25 (2.5)	0.84 (234)	0.404
	Part-time (n=19)	10.74 (3.4)		
Support of the Family Unit	Full-time (n=217)	17.47(3.1)	0.27(234)	0.790
	Part-time (n=19)	17.26 (3.6)		
Involvement of Child and Family in communication … etc.	Full-time (n=217)	14.78 (3.0)	1.16(234)	0.246
	Part-time (n=19)	13.95 (3.3)		
Relief of Pain and Other Symptoms	Full-time (n=217)	18.86 (2.3)	0.31(234)	0.754
	Part-time (n=19)	18.68 (2.1)		
Continuity of Care	Full-time (n=217)	10.36 (2.4)	1.12(234)	0.264
	Part-time (n=19)	9.68 (3.5)		
Grief and Bereavement Support	Full-time (n=217)	22.12 (2.6)	0.03(234)	0.976
	Part-time (n=19)	22.11 (3.0)		

Data in table 4.4 showed that there are no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey scores according to age-group in all subscale areas based on age-group.

Table 4.4: The nurses' attitude survey scores according to Age-group (One Way ANOVA)

Variables	Age-group	Mean	F statistics (df)	P-value
Holistic Care of the Child	20-24	11.29 (2.6)	0.35 (4)	0.845
	25-29	11.34 (2.5)		
	30-34	11.03 (2.8)		
	35-39	10.63 (2.3)		
	40 yrs. and more	11.13 (2.9)		
Support of the Family Unit	20-24	17.92 (3.3)	1.67 (4)	0.161
	25-29	17.14(3.1)		
	30-34	17.55 (3.0)		
	35-39	16.11 (2.8)		
	40 yrs. and more	17.13 (3.3)		
Involvement of Child and Family in communication, 1decision making and care planning	20-24	14.75 (3.2)	0.22 (4)	0.927
	25-29	14.73 (2.7)		
	30-34	14.97(3.2)		
	35-39	14.32 (2.8)		
	40 yrs. and more	14.13(1.8)		
Relief of Pain and Other Symptoms	20-24	19.02 (2.2)	0.48 (4)	0.750
	25-29	18.81 (2.5)		
	30-34	18.76 (2.0)		
	35-39	18.26 (2.8)		
	40 yrs. and more	18.63 (1.8)		
Continuity of Care	20-24	10.30 (2.6)	0.28 (4)	0.889
	25-29	10.35 (2.5)		
	30-34	10.27 (2.8)		
	35-39	9.89 (2.0)		
	40 yrs. and more	11.00 (1.9)		
Grief and Bereavement Support	20-24	22.37 (2.9)	1.37 (4)	0.246
	25-29	21.88 (2.5)		
	30-34	22.55 (1.8)		
	35-39	21.11 (1.8)		
	40 yrs. and more	21.88 (2.9)		

As can be seen in table 4.5 that no significant differences at level (α ≤ 0.05) between the means of the nurses' attitude survey scores according to education in five out of the six subscale areas. Whereas a significant difference was detected in the area of Relief of Pain and Other Symptoms (α=0.017).

Table 4.5: The nurses' attitude survey scores according to Education (One Way ANOVA)

Variables	Level of education	Mean	F statistics (df)	P-value
Holistic Care of the Child	Diploma Bachelor Master	11.24(2.9) 11.05 (2.4) 12.14 (2.4)	1.69 (2)	0.186
Support of the Family Unit	Diploma Bachelor Master	17.93 (3.3) 16.08 (3.1) 18.09 (3.1)	2.31(2)	0.101
Involvement of Child and Family in communication...etc.	Diploma Bachelor Master	15.00 (3.2) 14.43 (2.9) 15.50 (3.1)	1.70(2)	0.185
Relief of Pain and Other Symptoms	Diploma Bachelor Master	18.57 (2.0) 18.79 (2.3) 20.14 (2.7)	4.18(2)	0.017
Continuity of Care	Diploma Bachelor Master	10.53 (2.7) 10.07 (2.4) 11.05 (2.4)	1.88(2)	0.155
Grief and Bereavement Support	Diploma Bachelor Master	22.17 (2.5) 22.06 (2.7) 22.36 (2.9)	0.15(2)	0.862

Table 4.6 showed that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey scores according to years of nursing experience in all subscale areas.

Table 4.6: The nurses' attitude survey scores according to years of experience (One Way ANOVA)

Variables	Years of experience	Mean	F statistics (df)	P-value
Holistic Care of the Child	Less than 2 yrs.	11.66 (2.5)	0.67 (4)	0.612
	2-5	11.19 (2.5)		
	6-10	10.91 (2.9)		
	11-20	10.90 (2.7)		
	More than 20	11.50 (1.9)		
Support of the Family Unit	Less than 2 yrs.	18.17 (3.1)	1.27(4)	0.284
	2-5	17.35 (3.2)		
	6-10	17.43 (3.0)		
	11-20	16.63 (3.2)		
	More than 20	16.75 (5.5)		
Involvement of Child and Family in communication, decision making and care planning	Less than 2 yrs.	15.20 (3.3)	0.57(4)	0.684
	2-5	14.51 (2.8)		
	6-10	14.80 (3.1)		
	11-20	14.50 (3.0)		
	More than 20	14.00 (2.9)		
Relief of Pain and Other Symptoms	Less than 2 yrs.	18.91 (2.3)	1.10(4)	0.357
	2-5	19.00 (2.2)		
	6-10	18.93 (2.4)		
	11-20	18.27 (2.3)		
	More than 20	17.25 (1.0)		
Continuity of Care	Less than 2 yrs.	10.34 (2.7)	0.43(4)	0.784
	2-5	10.45 (2.4)		
	6-10	10.07 (2.7)		
	11-20	10.00 (2.3)		
	More than 20	11.25 (1.7)		
Grief and Bereavement Support	Less than 2 yrs.	22.23 (2.8)	0.56(4)	0.693
	2-5	22.24 (2.7)		
	6-10	22.07 (2.3)		
	11-20	21.83 (2.1)		
	More than 20	20.50 (2.9)		

Table 4.7 showed that no significant differences at the level (α≤ 0.05) between the means of the nurses’ attitude survey scores according to nurses’ position in all subscale areas.

Table 4.7: The nurses’ attitude survey scores according to nurses’ position (One Way ANOVA)

Variables	Nurses’ position	Mean	F statistics (df)	P-value
Holistic Care of the Child	Head nurse	11.50 (2.7)	0.36 (3)	0.784
	Assistant head nurse	10.69 (2.3)		
	Staff nurse	11.17 (2.4)		
	Practical nurse	11.33 (2.9)		
Support of the Family Unit	Head nurse	18.00 (3.1)	1.48(3)	0.220
	Assistant head nurse	17.19 (3.2)		
	Staff nurse	17.10 (3.1)		
	Practical nurse	18.00 (3.3)		
Involvement of Child and Family in communication...etc.	Head nurse	15.33 (2.4)	1.10 (3)	0.347
	Assistant head nurse	14.19 (3.1)		
	Staff nurse	14.48 (2.9)		
	Practical nurse	15.11 (3.2)		
Relief of Pain and Other Symptoms	Head nurse	18.67 (3.1)	1.88(3)	0.133
	Assistant head nurse	20.00 (2.9)		
	Staff nurse	18.90 (2.3)		
	Practical nurse	18.53 (2.0)		
Continuity of Care	Head nurse	9.78 (2.2)	0.94(3)	0.420
	Assistant head nurse	10.50 (2.7)		
	Staff nurse	10.15 (2.4)		
	Practical nurse	10.67 (2.7)		
Grief and Bereavement Support	Head nurse	21.56 (3.0)	0.33(3)	0.801
	Assistant head nurse	22.00 (2.4)		
	Staff nurse	22.17 (2.7)		
	Practical nurse	22.21 (2.5)		

Table 4.8 revealed that, there were significant differences at the level (α ≤ 0.05) between the means of the nurses’ attitude survey scores according to # of pediatric deaths in the following subscale areas: Holistic Care of the Child (p=0.015), Support of

the Family Unit (p=0.036), and Continuity of Care (p=0.018). On the other hand, no significant differences were detected in the other three subscale areas. These areas were: Involvement of Child and Family in communication...etc. (p=0.107), Grief and Bereavement Support (p=0.718), and Relief of Pain and Other Symptoms (p=0.268).

Table 4.8: The nurses' attitude survey scores according to # of pediatric deaths (One Way ANOVA)

Variables	# of pediatric deaths	Mean	F statistics (df)	P-value
Holistic Care of the Child	1-20 (n=185)	11.44(2.5)	4.29 (2)	<u>0.015</u>
	21-40 (n=33)	10.70(2.7)		
	More than 40 deaths (n=18)	9.78 (2.3)		
Support of the Family Unit	1-20 (n=185)	17.71 (3.1)	3.38(2)	<u>0.036</u>
	21-40 (n=33)	16.82 (3.6)		
	More than 40 deaths (n=18)	15.94 (2.6)		
Involvement of Child and Family in communication...etc.	1-20 (n=185)	14.91(3.0)	2.25(2)	0.107
	21-40 (n=33)	14.27 (3.1)		
	More than 40 deaths (n=18)	13.50 (3.1)		
Relief of Pain and Other Symptoms	1-20 (n=185)	18.90 (2.4)	1.33(2)	0.268
	21-40 (n=33)	18.97 (2.1)		
	More than 40 deaths (n=18)	18.00 (1.4)		
Continuity of Care	1-20 (n=185)	10.51 (2.4)	4.07(2)	<u>0.018</u>
	21-40 (n=33)	9.97 (3.1)		
	More than 40 deaths (n=18)	8.83 (2.0)		
Grief and Bereavement Support	1-20 (n=185)	22.08 (2.6)	0.33(2)	0.718
	21-40 (n=33)	22.45 (2.9)		
	More than 40 deaths (n=18)	21.94 (2.1)		

Table 4.9 revealed that, there were significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey scores according to # of admissions in all subscale areas including: Holistic Care of the Child (p <0.001), Support of the

Family Unit (p=0.002), Involvement of Child and Family in communication...etc. (p<0.001), Continuity of Care (p=0.001). Whereas no significant differences were detected in the following subscale areas: Relief of Pain and Other Symptoms (p=0.407), and Grief and Bereavement Support (p=0.119).

Table 4.9: The nurses' attitude survey scores according to # of admissions (One Way ANOVA)

Variables	# of admissions	Mean	F statistics (df)	P-value
Holistic Care of the Child	1-20 (n=50)	10.42 (2.7)	10.49 (2)	<0.001
	21-40 (n=39)	10.08 (2.4)		
	More than 40 deaths (n=147)	11.78 (2.4)		
Support of the Family Unit	1-20 (n=50)	16.50 (3.3)	6.34(2)	0.002
	21-40 (n=39)	16.56 (2.8)		
	More than 40 deaths (n=147)	18.01 (3.1)		
Involvement of Child and Family in communication...etc.	1-20 (n=50)	13.66(3.2)	9.39(2)	<0.001
	21-40 (n=39)	13.67 (2.8)		
	More than 40 deaths (n=147)	15.35 (2.8)		
Relief of Pain and Other Symptoms	1-20 (n=50)	18.76 (1.7)	0.90(2)	0.407
	21-40 (n=39)	18.44 (1.6)		
	More than 40 deaths (n=147)	18.98 (2.6)		
Continuity of Care	1-20 (n=50)	9.86 (2.8)	7.40(2)	0.001
	21-40 (n=39)	9.18 (2.4)		
	More than 40 deaths (n=147)	10.76 (2.4)		
Grief and Bereavement Support	1-20 (n=50)	21.90 (2.8)	2.15(2)	0.119
	21-40 (n=39)	21.46 (2.4)		
	More than 40 deaths (n=147)	22.37 (2.6)		

Table 4.10 revealed that, there were significant differences at the level (α ≤ 0.05) between the means of the nurses' attitude survey scores according to type of ward in the following subscale areas: Holistic Care of the Child (p=0.013), Involvement of Child

and Family in communication...etc. (p=0.005), and Continuity of Care (p=0.015). On the other hand, no significant differences were detected in the other two subscale areas. These areas were: Support of the Family Unit (p=0.164), Grief and Bereavement Support (p=0.979), and Relief of Pain and Other Symptoms (p=0.970).

Table 4.10: The nurses' attitude survey scores according to type of ward (One Way ANOVA)

Variables	Type of ward	Mean	F statistics (df)	P-value
Holistic Care of the Child	PW (n=139)	11.13 (2.6)	3.26 (4)	0.013
	PICU (n=50)	10.68 (2.7)		
	Pediatric cardiology (n=20)	12.80 (1.7)		
	Pediatric cardiology (n=24)	11.17 (2.1)		
	Pediatric oncology (n=3)	13.67 (1.5)		
Support of the Family Unit	PW (n=139)	17.67 (3.2)	1.90(4)	0.111
	PICU (n=50)	16.64 (3.1)		
	Pediatric cardiology (n=20)	17.80 (3.0)		
	Pediatric cardiology (n=24)	17.17 (2.8)		
	Pediatric oncology (n=3)	20.67 (0.6)		
Involvement of Child and Family in communication, decision making and care planning	PW (n=139)	14.68 (3.0)	3.82(4)	0.005
	PICU (n=50)	13.70 (3.0)		
	Pediatric cardiology (n=20)	16.40 (2.8)		
	Pediatric cardiology (n=24)	15.42 (2.7)		
	Pediatric oncology (n=3)	16.67 (2.5)		
Relief of Pain and Other Symptoms	PW (n=139)	18.81 (2.2)	0.13(4)	0.970
	PICU (n=50)	18.82 (2.4)		
	Pediatric cardiology (n=20)	18.00 (3.3)		
	Pediatric cardiology (n=24)	19.00 (1.8)		
	Pediatric oncology (n=3)	19.67 (2.1)		
Continuity of Care	PW (n=139)	10.32 (2.5)	3.15(4)	0.015
	PICU (n=50)	9.46 (2.5)		
	Pediatric cardiology (n=20)	11.60(2.6)		
	Pediatric cardiology (n=24)	10.88 (2.1)		
	Pediatric oncology (n=3)	10.33 (2.8)		
Grief and	PW (n=139)	20.06 (3.2)	0.11(4)	0.979

Bereavement Support	PICU (n=50)	19.32 (3.3)
	Pediatric cardiology (n=20)	21.60 (2.8)
	Pediatric cardiology (n=24)	20.50 (2.6)
	Pediatric oncology (n=3)	17.33 (3.1)

4.3 Descriptive Results for API Scales

4.3.1 Holistic care:

Table 4.11 Showed that the majority of the participants answered “often,” and “always” to each item on the scale, with combined results for those two levels of response as high as 64.0% (Question 14). Only 2.1% responded “Never” to one question on this scale, while 10.6% answered “rarely” to any item.

Table 4.11: Frequency Distribution of Holistic Care sub- Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
8. Quality of life	2.1	11.9	22.9	27.5	35.6
14. Referrals and interventions	2.1	10.6	23.3	36.0	28.0
39. Assessment of sources of suffering of the child	1.7	12.7	33.1	27.5	25.0

4.3.2 Support of Family

Overall responses to Support of Family scale items as shown in Table 4.12 were positive. Nursing staff believed that families and children got the help they need in obtaining practical, spiritual, and emotional support, as reflected by 56.8% answering “often” or “always” to Question 19. This question related in part to Question 9 specifically regarding assessment of spiritual needs. When asked if spiritual needs of the patient and family were addressed, 58.5% of the respondents answered “often” or “always.” Participants generally felt that all sources of suffering were addressed, with 56.4% responding often” or “always” to Question 27. Sibling involvement was also included in this scale. It appeared that there were fewer consensuses that siblings were involved and informed in the care of the child, with only 55.5% responding “often” or “always.”

Table 4.12: Frequency Distribution of Support of Family sub- Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
9. Spiritual needs of patient/family addressed	0.8	12.3	28.4	30.1	28.4
11. Sibling involvement	4.2	14.0	26.3	27.1	28.4
12. Lack of attention to spiritual needs of families	9.7	18.2	30.1	26.3	15.7
19. Help in obtaining practical, spiritual and emotional support	3.0	11.4	28.8	35.6	21.2
27. Assessment of sources of suffering of the family	2.1	10.6	30.9	28.0	28.4

4.3.3 Involvement of Child/Family in Decision making and Care:

However, Table 4.13 showed a less positive response to the question about medical futility. The nurses stated that 51.3% of the time, clinicians and parents agree "often" or "always" on what constitutes medical futility in child care. Paragraph (24) which stated that "Discussion of treatment options regarding impact on child’s quality of life" ranked last with a relative weight of (43.7%) which reflected the responses of the sample study on this paragraph. The need to pay attention to support all patients in making informed medical decisions that are consistent with their needs, values, and preferences.

Table 4.13: Frequency Distribution of Involvement of Child/Family sub - Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
16. In determining treatment goals and plans	0.4	7.6	26.7	32.6	32.6
24. Discussion of treatment options regarding impact on	11.0	17.8	27.5	26.3	17.4
25. Staff finds out parents/families wants for	4.7	10.2	30.5	33.5	21.2
38. Agreement about medical futility	2.5	9.3	36.9	26.7	24.6

4.3.4 Continuity of Care

Table 4.14 showed the frequency distribution of these questions. The largest frequencies among the three items on the scale were related to the designated coordinator (Question 34), with 57.2% of responses "often" or "always".

Table 4.14: Frequency Distribution of Continuity of Care sub- Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
31. Collaboration of primary care providers and specialists	3.4	17.8	29.2	31.8	17.8
32. Written plan of care	5.9	17.4	33.9	31.8	11.0
34. Designated coordinator	2.5	14.0	26.3	32.2	25.0

4.3.5 Grief / Bereavement

Table 4.15 showed the frequency distribution of the Grief / Bereavement scale. There was a positive response to indicate that the staff approach and offer emotional support to a member of the family who is openly afflicted, as 57.6% answered "often" or "always" to this element. Nurses specified that they considered it appropriate for colleagues to comfort each other when a patient dies, with 58.1% responding "always" or "often". More than half (52.1%) feel that "often" or "always" there were enough opportunities for staff to support each other in the death of a child. Almost less than a quarter (19.5%) of the nurses responded "often" or "always" that the support of grieving families after the death of a child is inadequate. Interestingly, the survey results indicated that, because it is so unpleasant, 27.1% actually tried to avoid caring for a dying child "often" or "always".

Table 4.15: Frequency Distribution of Grief/Bereavement sub- Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
17. Objectivity and showing little emotion best	24.2	31.8	33.9	7.2	3.0
26. Offer emotional support to openly grieving family member	3.4	9.3	29.7	33.9	23.7
30. Avoidance of caring for a dying child	16.5	25.4	30.9	17.4	9.7
35. Inadequate bereavement support after child’s death	21.6	29.7	29.2	15.7	3.8
36. Freedom to display emotion at child’s death	4.7	11.0	29.2	30.1	25.0
37. Opportunities for staff to support one another	3.0	13.1	31.8	27.5	24.6
40. Appropriateness of colleagues consoling one another	2.5	7.6	31.8	35.6	22.5

4.4 Inferential Hypothesis for Barriers Scales

Table 4.16 showed that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey according to gender in all subscale areas.

Table 4.16: The nurses' barrier survey scores according to Gender (independent t Test)

Variables	Gender	Mean	*t* statistics (df)	P-value
Complex Care Issues	Male	20.41 (4.1)	-1.14 (234)	0.255
	Female	21.09 (4.3)		
Nursing Educational/ Psychological Issues	Male	12.99 (2.6)	-0.67	0.505
	Female	13.28 (3.1)		
Palliative/Curative Care Issues	Male	13.15 (2.3)	-0.43	0.666
	Female	13.32 (3.1)		
Conflicts Involving Family and/or Staff	Male	12.04 (2.9)	-1.34	0.183
	Female	12.62 (3.2)		
Program and Staffing Barriers	Male	10.24 (2.2)	-0.63	0.529
	Female	10.46 (2.5)		

Table 4.17 showed that there is a significant difference at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey according to employment status in two subscales out of five. These subscale areas were: Palliative / Curative Care Issues (p=0.007), and Program and Staffing Barriers (p=0.026), whereas, no significant differences were detected in the other areas.

Table 4.17: The nurses' barrier survey scores according to employment status (independent t- Test)

Variables	Employment status	Mean	*t* statistics (df)	P-value
Complex Care Issues	Full-time (n=217)	20.91 (4.1)	0.48 (234)	0.630
	Part-time (n=19)	20.42 (5.8)		
Nursing Educational/ Psychological Issues	Full-time (n=217)	13.28 (2.9)	1.81 (234)	0.072
	Part-time (n=19)	12.00 (3.3)		
Palliative/Curative Care Issues	Full-time (n=217)	13.41 (2.7)	2.74 (234)	0.007
	Part-time (n=19)	11.58 (4.0)		
Conflicts Involving Family and /or Staff	Full-time (n=217)	12.53 (3.1)	1.49 (234)	0.137
	Part-time (n=19)	11.42 (3.1)		
Program and Staffing Barriers	Full-time (n=217)	10.49 (2.4)	2.24 (234)	0.026
	Part-time (n=19)	9.21 (2.7)		

Table 4.18 showed that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey scores according to level of education in all subscale areas.

Table 4.18: The nurses' barrier survey scores according to Education (One Way ANOVA)

Variables	Level of education	Mean	F statistics (df)	P-value
Complex Care Issues	Diploma	21.29 (4.9)	0.59 (2)	0.555
	Bachelor	20.63 (4.0)		
	Master	20.95 (3.6)		
Nursing Educational/ Psychological Issues	Diploma	13.28 (3.5)	1.01 (2)	0.365
	Bachelor	13.26 (2.7)		
	Master	12.32 (2.3)		
Palliative/Curative	Diploma	13.13 (3.4)	0.13 (2)	0.881

Care Issues	Bachelor	13.33 (2.6)		
	Master	13.32 (2.6)		
Conflicts Involving Family and/or Staff	Diploma	12.68 (3.5)	0.62 (2)	0.538
	Bachelor	12.40 (3.0)		
	Master	11.86 (2.3)		
Program and Staffing Barriers	Diploma	10.61 (2.7)	1.18 (2)	0.309
	Bachelor	10.20 (2.2)		
	Master	10.86 (2.4)		

Table 4.19 showed that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' attitude survey scores according to years of nursing experience in all subscale areas.

Table 4.19: The nurses' barrier survey scores according to years of experience (One Way ANOVA)

Variables	Years of experience	Mean	F statistics (df)	P-value
Complex Care Issues	Less than 2 yrs. (n=53)	21.89 (4.5)	1.81 (4)	0.128
	2-5 (n=103)	20.71 (3.8)		
	6-10 (n=46)	20.30 (4.6)		
	11-20 (n=30)	24.00 (4.4)		
	More than 20 yrs. (n=8)	11.50 (6.0)		
Nursing Educational/ Psychological Issues	Less than 2 yrs. (n=53)	13.94 (3.2)	1.72(4)	0.147
	2-5 (n=103)	12.95 (2.7)		
	6-10 (n=46)	12.59 (3.4)		
	11-20 (n=30)	13.33 (2.3)		
	More than 20 yrs. (n=8)	14.50 (5.3)		
Palliative/Curative Care Issues	Less than 2 yrs. (n=53)	13.55 (3.4)	0.41(4)	0.799

	2-5 (n=103)	13.01 (2.6)		
	6-10 (n=46)	13.35 (2.8)		
	11-20 (n=30)	13.40 (2.6)		
	More than 20 yrs. (n=8)	14.00 (2.3)		
Conflicts Involving Family and /or Staff	Less than 2 yrs.	12.87 (3.3)	0.41(4)	0.798
	2-5 (n=103)	12.37 (3.0)		
	6-10 (n=46)	12.13 (3.3)		
	11-20 (n=30)	12.33 (3.2)		
	More than 20 yrs. (n=8)	13.00 (2.4)		
Program and Staffing Barriers	Less than 2 yrs.	10.87 (2.7)	1.26(4)	0.288
	2-5 (n=103)	10.36 (2.4)		
	6-10 (n=46)	9.89 (2.5)		
	11-20 (n=30)	10.27 (2.4)		
	More than 20 yrs. (n=8)	11.50 (2.4)		

Table 4.20 showed that there were no significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey scores according to nurses' position in all subscale areas.

Table 4.20: The nurses' barrier survey scores according to nurses' position (One Way ANOVA)

Variables	Nurses' position	Mean	F statistics (df)	P-value
Complex Care Issues	Head nurse (n=18)	21.22 (4.3)	0.63 (3)	0.598
	Assistant head nurse (n=16)	20.88 (3.1)		
	Staff nurse (n=130)	20.55 (3.9)		
	Practical nurse (n=72)	21.38 (5.0)		
Nursing Educational/ Psychological Issues	Head nurse (n=18)	13.28 (2.2)	0.12(3)	0.951
	Assistant head nurse (n=16)	12.81 (2.1)		
	Staff nurse (n=130)	13.15 (2.8)		
	Practical nurse (n=72)	13.28 (3.6)		

Palliative/Curative Care Issues	Head nurse (n=18)	13.33 (2.1)	0.18(3)	0.911
	Assistant head nurse (n=16)	12.94 (2.2)		
	Staff nurse (n=130)	13.37 (2.7)		
	Practical nurse (n=72)	13.14 (3.4)		
Conflicts Involving Family and/or Staff	Head nurse (n=18)	11.72 (2.7)	0.37(3)	0.777
	Assistant head nurse (n=16)	12.56 (2.9)		
	Staff nurse (n=130)	12.45 (3.0)		
	Practical nurse (n=72)	12.57 (3.5)		
Program and Staffing Barriers	Head nurse (n=18)	10.06 (2.4)	0.62(3)	0.602
	Assistant head nurse (n=16)	9.81 (2.2)		
	Staff nurse (n=130)	10.38 (2.3)		
	Practical nurse (n=72)	10.61 (2.7)		

Table 4.21 showed that, there were significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey scores according to # of pediatric deaths in the following subscale areas: Complex Care Issues ($p < 0.001$), and Program and Staffing Barriers (p=0.010). On the other hand, no significant differences were detected in the other two subscale areas. These areas were: Nursing Educational/ Psychological Issues (p=0.158), Palliative/Curative Care Issues (p=380), and Conflicts Involving Family and/or Staff (p=0.760).

Table 4.21: The nurses' barrier survey scores according to # of pediatric deaths (One Way ANOVA)

Variables	# of pediatric deaths	Mean	F statistics (df)	P-value
Complex Care Issues	1-20 (n=185)	21.44(4.2)	8.17 (2)	< 0.001
	21-40 (n=33)	19.06(3.7)		
	More than 40 deaths (n=18)	18.39 (3.7)		
Nursing Educational/ Psychological Issues	1-20 (n=185)	13.38 (3.0)	1.86(2)	0.158
	21-40 (n=33)	12.42 (2.8)		
	More than 40 deaths (n=18)	12.56 (3.0)		
Palliative/Curative Care Issues	1-20 (n=185)	13.23(2.9)	0.97(2)	0.380
	21-40 (n=33)	13.79 (2.6)		
	More than 40 deaths (n=18)	12.67 (2.8)		
Conflicts Involving Family and/or Staff	1-20 (n=185)	12.52 (3.1)	0.28(2)	0.760
	21-40 (n=33)	12.12 (3.4)		
	More than 40 deaths (n=18)	12.22 (3.0)		
Program and Staffing Barriers	1-20 (n=185)	10.64 (2.4)	4.68(2)	0.010
	21-40 (n=33)	9.48 (2.6)		
	More than 40 deaths (n=18)	9.50 (2.1)		

Table 4.22 revealed that, there were significant differences at the level (α ≤ 0.05) between the means of the nurses' barrier survey scores according to # of admissions in all subscale areas including: Complex Care Issues (p = 0.002), Nursing Educational/ Psychological Issues (p=0.010), Program and Staffing Barriers (p<0.001). Whereas no significant differences in the other subscales.

Table 4.22: The nurses' barrier survey scores according to # of admissions (One Way ANOVA)

Variables	# of admissions	Mean	F statistics (df)	P-value
Complex Care Issues	1-20 (n=50) 21-40 (n=39) More than 40 deaths (n=147)	20.22 (4.7) 19.08 (3.6) 21.57 (4.1)	6.32 (2)	<u>0.002</u>
Nursing Educational/ Psychological Issues	1-20 (n=50) 21-40 (n=39) More than 40 deaths (n=147)	12.20 (3.8) 12.79 (2.8) 13.61 (2.9)	4.73(2)	<u>0.010</u>
Palliative/Curative Care Issues	1-20 (n=50) 21-40 (n=39) More than 40 deaths (n=147)	12.60 (3.2) 12.92 (2.4) 13.59 (2.8)	2.62(2)	<u>0.075</u>
Conflicts Involving Family and/or Staff	1-20 (n=50) 21-40 (n=39) More than 40 deaths (n=147)	12.04 (3.1) 11.90 (3.2) 12.72 (3.1)	1.61(2)	0.202
Program and Staffing Barriers	1-20 (n=50) 21-40 (n=39) More than 40 deaths (n=147)	9.84 (2.4) 9.36 (2.5) 10.39 (2.4)	8.01(2)	<u><0.001</u>

Table 4.23 showed that, there were no significant differences at the level (α ≤ 0.05) between the means of the nurses' barrier survey scores according to type of ward in all subscale areas.

Table 4.23: The nurses' attitude survey scores according to type of ward (One Way ANOVA)

Variables	Type of ward	Mean	F statistics (df)	P-value
Complex Care Issues	PW (n=139)	20.71 (4.4)	1.30 (4)	0.270
	PICU (50)	20.84 (4.3)		
	Pediatric cardiology (n=20)	22.35 (3.7)		
	Pediatric cardiology (n=24)	20.21 (3.1)		
	Pediatric oncology (n=3)	24.33 (4.9)		
Nursing Educational/ Psychological Issues	PW (n=139)	13.18 (3.1)	0.97 (4)	0.426
	PICU (50)	12.66 (2.6)		
	Pediatric cardiology (n=20)	13.85 (2.5)		
	Pediatric cardiology (n=24)	13.46 (3.0)		
	Pediatric oncology (n=3)	15.00 (4.4)		
Palliative/Curative Care Issues	PW (n=139)	13.20 (2.9)	1.73 (4)	0.144
	PICU (50)	12.66 (2.8)		
	Pediatric cardiology (n=20)	14.30 (2.5)		
	Pediatric cardiology (n=24)	13.88 (2.7)		
	Pediatric oncology (n=3)	14.67 (5.0)		
Conflicts Involving Family and/or Staff	PW (n=139)	12.32 (3.2)	2.32 (4)	0.058
	PICU (50)	11.92 (2.9)		
	Pediatric cardiology (n=20)	12.35 (2.1)		
	Pediatric cardiology (n=24)	14.04 (2.0)		
	Pediatric oncology (n=3)	14.33 (5.0)		
Program and Staffing Barriers	PW (n=139)	10.42 (2.6)	1.86 (4)	0.119
	PICU (50)	10.18 (2.2)		
	Pediatric cardiology (n=20)	10.35(2.1)		
	Pediatric cardiology (n=24)	11.50 (1.3)		
	Pediatric oncology (n=3)	12.39 (2.4)		

Table 4.24 indicated that there is no significant difference at the level ($\alpha \leq 0.05$) between the means of the nurses' barrier survey scores according to age-group in subscale areas.

Table 4.24: The nurses' attitude survey scores according to Age-group (One Way ANOVA)

Variables	**Age-group**	**Mean**	**F statistics (df)**	**P-value**
Complex Care Issues	20-24 (n=102)	21.11 (4.3)	0.82 (4)	0.515
	25-29 (n=74)	21.19 (3.9)		
	30-34 (n=33)	20.21 (4.7)		
	35-39 (n=19)	19.58 (3.8)		
	40 yrs. and more (n=8)	20.75 (6.2)		
Nursing Educational/ Psychological Issues	20-24 (n=102)	13.26 (3.1)	0.35(4)	0.845
	25-29 (n=74)	13.34 (2.7)		
	30-34 (n=33)	12.88 (3.5)		
	35-39 (n=19)	12.58 (2.2)		
	40 yrs. and more (n=8)	13.25 (4.2)		
Palliative/Curative Care Issues	20-24 (n=102)	13.16 (3.1)	0.23(4)	0.924
	25-29 (n=74)	13.51 (2.6)		
	30-34 (n=33)	13.06 (3.3)		
	35-39 (n=19)	13.32 (1.7)		
	40 yrs. and more (n=8)	13.13 (2.1)		

Conflicts Involving Family and/or Staff	20-24 (n=102)	12.42 (3.3)	0.36(4)	0.834
	25-29 (n=74)	12.35 (3.0)		
	30-34 (n=33)	12.94 (3.0)		
	35-39 (n=19)	12.37 (3.1)		
	40 yrs. and more (n=8)	11.63 (2.8)		
Program and Staffing Barriers	20-24 (n=102)	10.53 (2.5)	0.21(4)	0.935
	25-29 (n=74)	10.35 (2.2)		
	30-34 (n=33)	10.27 (2.7)		
	35-39 (n=19)	10.05 (2.1)		
	40 yrs. and more (n=8)	10.25 (3.2)		

4.5 Descriptive Results for Barriers Scales

4.5.1 Complex Care Issues:

Table 4.25 showed that more than a third (47.4%) of nurses reported consistency and coordination of complex care among multiple providers as an impediment to care “often,” and “always”. Approximately 52.5% of respondents stated that “often” or “always” the availability of pain and symptom management experts was problematic. Patient and family psychological and / or emotional needs were a frequent or continuous obstacle, according to 63.2% of respondents. Conflicts with other professionals was cited as a barrier to care “often” or “always” by only 40.7% of participants in the study.

Table 4.25: Frequency Distribution of Complex Barriers sub - Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
41. Consistency and coordination of complex care among multiple providers	3.0	15.3	34.3	27.5	19.9
42. Availability of pain and symptom management experts	1.7	8.9	36.9	34.7	17.8
43. Psychological and/or emotional needs	4.2	8.5	33.1	30.9	23.3
44. Spiritual needs	3.4	9.7	34.7	38.1	14.0
45. Conflicts with other professionals	3.0	17.8	38.6	27.1	13.6
49. Cultural views of family	1.3	13.6	41.9	28.0	15.3

4.5.2 Educational and/or Psychological Issues:

The frequency distribution of Educational/Psychological Barriers scale items were reported in Table 4.26. Slightly more than one-third (39.8%) of nurses who completed the survey stated that lack of palliative care training was problematic “often” or “always”. Another barrier question in the survey related to limited experience with palliative care. Approximately 41.1% of the nurses responding to the questionnaire reported that limited experience impeded quality care. When asked about task of caring for children with life threatening conditions being emotionally draining, 40.7% answered “often” or “always” to this item. Discomfort in delivering bad news to patients and families was reported by 36.4% who responded “often” or “always” to this question.

Table 4.26: Frequency Distribution of Educational/Psychological Barriers sub-Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
48. Lack of palliative care training	3.0	19.5	37.7	26.7	13.1
50. Emotionally draining for provider	2.5	14.4	42.4	26.3	14.4
51. Limited experience with palliative care	4.7	14.8	39.4	29.2	11.9
53. Comfort level in delivering bad news	3.0	14.4	46.2	26.7	9.7

4.5.3 Palliative vs. Curative Care Issues:

Table 4.27 showed the frequency distribution of Palliative vs. Curative Care issues. Participants were asked to rate the extent that the belief of family, caregivers, and physicians that palliative and hospice care are “giving up” was a barrier to care of patients. A fewer number of nurses (41.6%) responded “often” or “always” regarding family beliefs that hospice/palliative care are “giving up,” compared to that of the caregiver (38.1%) or physician beliefs (43.6%) about this issue. Only 42.4% responded “often” or “always” that reimbursement systems were an impediment to care.

Table 4.27: Frequency Distribution of Palliative vs. Curative Care sub- Scale Items

Survey item	Never %	Rarely %	Sometimes %	Often %	Always %
46. Reimbursement	1.7	13.1	42.8	28.0	14.4
54. Caregiver belief hospice/ palliative care separate from curative	4.7	20.8	36.4	27.5	10.6
55. Family belief hospice/ palliative care are “giving up”	2.1	15.7	40.7	33.1	8.5
56. Physician belief hospice/ palliative care are “giving up”	4.2	12.3	39.8	28.8	14.8

Chapter Five:

Discussion and Recommendations

5.1 Discussion

Caring for children with life-threatening conditions and their families is a complex and challenging task. As attention to pediatric palliative care is growing, a better understanding of the attitudes, practices, and problems that caregivers face in delivering services to this population is needed. A comprehensive review of literature suggests that the participants in most studies on this topic have been physicians and that little research has been done that directly related to nursing staff. Although children with life-threatening conditions often receives services from more than one subspecialty in a hospital institutional setting and are likely to encounter many nurses from multiple departments, no studies in the review of literature compares data across nursing subspecialties at a single institution.

The literature shows that there were a number of barriers to caring for these children. Reimbursement issues, continuity of care, difficulties in communication, as well as conflicting views about palliative and curative treatment are among obstacles that impede excellence in care. Potential barriers occurred at three different levels: patient level, provider level and system level. The barriers at patient level are related to the patient characteristics: demographic variables, social structure variables, health beliefs and attitudes, personal enabling resources, community enabling resources, perceive illness and personal health practices. The barriers at provider level relate to the provider characteristics: skills and attitudes. The barriers at system level were related to the system characteristics: the organization of the health care system.

5.1.1 Attitudes and Practices

The description of attitude scores shows respondents ‘have a favorable attitude towards palliative care. This finding are in agreement with the findings of (Kassa et al., 2014) and many results of other studies find the data contrary to this research (Ayed et al., 2015; Zahhreddine, Hazeim, Assi, Emara 2013).

5.1.2 Holistic Care Scale:

Holistic care focuses on supporting the needs of each child with a life-threatening condition, ensuring that their potential is promoted in six areas, including physical, social, emotional, developmental, spiritual and educational. In general, the participants responses are positive on this scale.

The description of holistic care scale shows respondents have affordable toward palliatives care. this finding is in agreement with the findings of (Zamanzadeh et al., 2015; Hamdan et al ,2017) and many results of other studies are contrary to this research(Morgan, 2009) .

5.1.3 Support of Family Scale:

The Support of Family scale includes questions regarding attention and/or assessment of the family’s spiritual, emotional, psychosocial, and physical needs. The description of holistic care scale showed respondents have favorable toward palliative care.

This finding are in agreement with the findings of (Kristjanson, and Aoun, 2004). and many results of other studies are in contrary to this research (Nascimento , 2016; Roets et al., 2012).

5.1.4 Involvement of Child / Family Scale

The nurses' responses to the child / family participation scale rate the staff's efforts to involve parents / family members in determining goals and treatment plans in a very positive way. Nearly 2/3 (65.2%) responses are "often" or "always" to this article. An even important number (54.7%) state that they discovered what parents / families want for their children.

This finding are in agreement with the findings of (Laura et al., 2016; Jones et al., 2014) and many results of other studies found the data are contrary to this research (Sudore et al., 2014; Vollenbroich, 2012).

5.1.5 The Continuity of Care scale:

The Continuity of Care scale rises questions related to practices that ensure seamless and uninterrupted care, thereby promoting trusted relationships with the healthcare team. Questions on this scale included inquiries about collaboration, written care plans and designated care coordinator. The general nursing responses to the items of the Continuity of Care scale are positive (M = 2.79).

This finding are in agreement with the findings of (Heller et al., 2005; Burge et al., 2003) and many results of other studies found the data are contrary to this research (Haggerty et al., 2003).

5.1.6 Grief / Bereavement scale:

Items on this scale are related to the support of families and staff, both before and after the death of a child. There is a positive response to indicate that the staff approach and offer emotional support to a member of the family.

The description of The Grief / Bereavement scale show respondents have favorable toward palliative care. This finding are in agreement with the findings of (Seecharan et al., 2004; van der Geest.et al., 2014) and many results of other studies found the data are contrary to this research (Chapman et al.,1998).

5.1.6 Barriers to Care

This finding are in agreement with the findings of (Kain, 2008) and (Khraisat et al., 2017) and many results of other studies found the data contrary to this research (Chapman, and Pepler, 1998) .

5.1.7 Complex Barriers Scale

Complexities are inherent in the multi-faceted challenges of caring for children with life-threatening conditions and include not only the coordination of care and expert pain and symptom management, but psychosocial issues that are psychological, spiritual or cultural in nature.

The description of The Barriers to Care show respondent's have favorable toward palliative care. This finding is in agreement with the findings of (Davies et al., 2008) and (Wiener et al., 2013). And many results of other studies found the data contrary to this research (Craig et al., 1996).and (Kajermo et al., 2010).

5.1.8 Educational/Psychological barriers scale

This finding are in agreement with the findings of (Hudson et al., 2009) and (Pace, and Lunsford, 2011), and many results of other studies found the data contrary to this research (Aleksandra et al., 2013).

5.1.9 Palliative vs. Curative Care Scale

The belief of family that palliative and hospice care are “giving up” posed a slightly greater barrier for nurses in caring for children with life-threatening conditions that the caregiver or physician belief regarding this issue.

The description of The Barriers to Care show respondents have favorable toward palliative care. This finding is in agreement with the findings of (Kaur, and Mohanti, 2011). and many results of other studies found the data contrary to this research (Löfmark et al., 2007).

5.1.10 Knowledge and attitude of pediatric nurses toward child with a life-threatening condition

There are significant differences at the level ($\alpha \leq 0.05$) between the means of the nurses’ knowledge and attitude in the following subscale areas:

1. This result is contrary to the result of study (Abu Hasheesh et al., 2013) where the results on death scale show no significant differences among the gender groups on the total scores. Meanwhile, significant difference exists in the fear of death subscale to the favor of females, suggesting that females has a tendency to exhibit fear of death toward care of dying patient. Also, this result was different to the result of study (Al Qadire , and Al Khalaileh, 2014).

This is a natural result that emphasizes the importance of knowledge in the ability of the nurse to deal with symptoms and relieve the patient's pain. This result coincided with many other studies, including (Aldridge et al., 2016; Williams- Reade et al., 2015; Stanley et al., 2013; Hossain et al., 2010).

These results confirm that improving holistic care of the child, support of the family unit and continuity of care, reducing the number of deaths and prolong patient survival. These findings coincid with the study (Grimley, 2011; Kain, 2008).

1. The results favor the lower number of admissions, this means, the smaller the number of children admitted, the greater the ability of nurses in all subscale areas including: holistic care of the child, support of the family, Involvement of child and family in communication, continuity of care. This is normal, since the increase in the number of number of children admitted increased the workload of nurses. These results were implicitly correlated with (Aldridge et al., 2016; Jaimovich, 2004).
2. In view of these results, all subscale areas including: holistic care of the child, support of the family unit, involvement of child and family in communication and continuity of care, are low in Pediatric Cardiology and Pediatric Oncology compare to the PW and PICU. By reviewing the data in Table 4.10, we noted a decrease in the number of Pediatric Cardiology and Oncology patients compared to the PW and PICU. These patients needed special care by specialized and highly qualified nurses. These sections also required modern equipment and may sometimes be complex and required highly trained staff to use. This may not be available in all hospitals. Within the limits of the researcher's knowledge, no study was found to examine the nurses’ attitude according to type of ward.

5.1.11 The nurses' barriers

1. Findings indicate a weakness or malfunction in Complex Care Issues and in Program and Staffing Barriers, which increased the number of deaths in children. These results are implicitly correlated with (Aldridge et al.,2016).

2. Results indicate that increased in number of admitted pediatric create problems or malfunction in areas of Complex Care Issues, Nursing Educational/ Psychological Issues, Palliative/Curative Care Issues and in Program and Staffing Barriers, which increases the number of deaths in children.

3. Patients and their families have a right to receive adequate pain assessment and management, and it is important for hospitals to be aware of their nurses' abilities to perform these tasks. It is important to note that pediatric nurses may feel a high level of self-efficacy. Also note that the years of nursing experience do not demonstrate a relationship with the level of pain management knowledge or self-efficiency. Nurses are continually faced with the challenge of treating pain, and to ensure the best quality of care for patients, nurses needed effective knowledge, skills, and attitudes to address pediatric pain needs.

5.2 Conclusion and Recommendations

Conclusion

Finally of my study, I find the important of the P.C in our country (Palestine) through Reflect on the need and access of the Palestinians living in the West Bank and Gaza Strip to palliative care; also defined the factors that might interfere with the proper introduction of palliative care; and Focused on the positive compensatory effect of religion and culture on palliative care.

Recommendations

Nursing practice

In order to improve palliative care in Palestine will required multi-institutional strategies. Such strategies should focus on establishing palliative care services at all levels of the Healthcare system and organize the training of the nurses about palliative care.

Nursing Education

Palliative care needs to become an integral part of all nursing school curricula and medical education program for undergraduate and postgraduate nurses that cover all aspects of palliative care, such as its principles and philosophy, communication, psychosocial support, pain and symptom management, and cultural views.

Nursing Research

More studies are needed in this area to clearly understand the problems met in the practice setting and to show the acceptance of a PC delivery model that is culturally sensitive and meets the needs of the Palestinian population.

Nursing Culture and Religious

Development nursing role through community training course for P.C and encourage on it, in the other hand the need for public awareness through teach family about P.C and nursing home to help and learn them.

Cooperation’s Institutions

The importance of networking and cooperation between the national NGO’s and the MOH.

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Appendices:

Appendix (1):

Attitude and Practice Inventory Question Guide

Domain	Goal	Survey Question Number	Type of Question
1. Holistic Care of the Child	1. The needs of each child with a life-threatening condition are supported and his/her potential promoted in the following six areas: physical, social, emotional, developmental, spiritual, and educational.	8	Attitude
		14	Practice
2. Support of the Family Unit	1. Each family of a child with a life-threatening condition receives the support and resources it needs to maintain its integrity.	9	Practice
		11	Practice
		12	Attitude
		19	Attitude
		27	Practice
3. Involvement of Child and	1. Each child with a life-	10	Attitude

Family in Communication, Decision Making and Care Planning	threatening condition is informed about and involved in decisions about his/her own care and care planning to the extent possible based on developmental abilities and desires.	13	Practice
		21	Practice
	2. The health care institution and providers support the opportunity for each family of a child with a life-threatening condition to be involved in decision-making and care planning with and for its child, respecting the level of involvement desired.	15	Practice
		16	Practice
		23	Practice
		25	Practice
4. Relief of Pain and Other Symptoms	1. Each child living with a life- threatening condition receives effective pain and symptom management.	18	Attitude
		20	Practice
		22	Attitude
		24	Attitude
		28	Practice

		29	Attitude
5. Continuity of Care	1. Each child with a life-threatening condition has a written plan of care, which is documented and communicated across all care settings.	31	Attitude
	2. Each child with a life-threatening condition has a designated individual, a physician or other health care provider, who is identified as responsible for coordinating the child's overall care.	32	Practice
6. Grief and Bereavement Support	1. Each family of a child with a life-threatening condition is offered grief and bereavement support before and after the child's death.	26	Practice
	2. Health care providers working with children with life- threatening conditions	17	Attitude
		30	Practice

	and their families are offered grief and bereavement support.

Appendix (2):

Five distinct issues that more accurately define the types of barriers that: nurse's encounter. These issues can be described as

	Domain	**Survey Question Number**
1.	**Complex Care Issues**	41, 42, 43, 44, 45, 49
2.	**Nursing Educational/Psychological Issues**	48, 50, 51, 53
3.	**Palliative/Curative Care Issues**	54, 55, 56
4.	**Conflicts Involving Family and/or Staff**	52, 57, 58, 59
5.	**Program and Staffing Barriers**	47, 60, 61

Appendix (3)

جامعة القدس
Al-Quds University

FACULTY OF HEALTH PROFESSIONS

DEPARTMENT OF NURSING

MASTER OF PEDIATRIC NURSING

Student:

Atheer Qashou

Supervisor

Dr. Farid Ghrayeb

2017/2018

Participant Cover Letter

I am a graduate student in the Master of Pediatric in Nursing Program at Nursing Department, Al-Quds University, in Palestine. I am conducting a study to examine the level of practice and attitude and barriers offer in pediatric word and intensive care unit at west bank hospital. You are invited to complete an anonymous questionnaire and demographic sheet. The questionnaire will take approximately twenty to thirty minutes to complete. Your participation in this study is voluntary and your responses are anonymous. Please do not include your name or any personal identifying markings on the questionnaires. You may withdraw at any time from the study. There will be no risk to you or any compensation given for taking this survey. Should you choose to participate; **the completion of the questionnaire will serve as informed consent.** At your request, results of the study will be made available to you. You are free to ask questions about the study or your participation in the study.

You may direct any questions to:

Dr. Farid Ghrayeb PhD, BS, RN,
Nursing Department, Faculty of Health Professions,
Al Quds University
Phone: 0597-590131
Email: fghrayeb@staff.alquds.edu

Thank you for your participation in this study.
Sincerely,
Atheer Qashoua
Phone: 0599034170
Email: aqashou13@gmail.com

Demographics

To the best of your ability, please complete the following about yourself and the pediatric Unit with which you are associated.

1) Gender: ☐ Male ☐ Female

2) Age: ☐ 20-25 ☐ 26-30 ☐ 31-36 ☐ 37-42 ☐ over >42

3) Material status: ☐ single ☐ married ☐ divorce ☐ widow

4) Employment status: Full time ☐ Part time ☐

5) Level of education: ☐ Diploma ☐ Bachalorus ☐ Master ☐ PHD

6) Years of Experience in Pediatric word:

☐ **Less than 1years.** ☐ **2-5 years.** ☐ **5-10years.** ☐ **10-20years.**

☐ **over than 20 years.**

7) What is your position and role in the unit?

☐ **Head nurse.** ☐ **Assistant for head nurse.** ☐ **Staff nurse.** ☐ **Practical nurse.**

8) Pediatric Deaths in this unit in the last year?

☐ 1-20 children. ☐ 20-40children. ☐ more than 40 children .

10) How many children were admitted to this unit in the last year? (*Exclude admissions for less than 24 hours)*. Admissions per year.

☐ 1-20 children. ☐ 20-40children. ☐ more than 40 children.

11) Name of the PW:

☐ PW. ☐ PICU. ☐ Pediatric Hematology/Oncology

☐ Pediatric Cardiology . ☐ Pediatric Oncology

Other (specify):____________________

Attitude and Practice

Six domains or areas of care for children with life threatening conditions and their families are outlined in the Initiative for Pediatric Palliative Care (Solomon et al., 2002), and include the following categories: (a) Holistic Care of the Child; (b) Support of the Family Unit; (c) Involvement of Child and Family in Communication; (d) Decision Making and Care Planning; (e) Relief of Pain and Other Symptoms; (f) Continuity of Care; and (g) Grief and Bereavement Support.

Items	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
1-All health care members caring for a child with a life-threatening condition make efforts to understand what the child/family value as quality of life.					
2- Spiritual needs of the patient/family are assessed and addressed					
3-Whenever possible, clinicians obtain consent from children, before proceeding with treatment					
4-Siblings are involved and informed in the care of the child with a life-threatening condition.					
5- We give too little attention at our institution to the spiritual needs of the families of critically and terminally ill					

children					
6- Staff finds out what children want for themselves (based on the child’s development).					
7- The needs of each child with a life-threatening condition are supported by referrals and appropriate interventions by Child Life, Social Workers, Physical Therapy and Psychology.					
8- When a child’s illness is clearly terminal, the medical staff works with the family to inform the child of their prognosis at the end of life in a developmental^ appropriate manner.					
9- Staff involves parents/family members in determining treatment goals and plans					
10- It is better that health care professionals remain objective and show little emotion in caring for a child with a terminal prognosis.					
11- “Aggressive measures,” such as intensive care, are not appropriate for patients with DNR orders.					

12- Parents/families and children get the help they need in obtaining practical, spiritual and emotional support.					
13- Children’s pain levels are closely monitored and pain medications are promptly adjusted.					
14- The child’s wishes are acted upon.					
15- When clinicians give inadequate pain medication they do so most often out of fear of hastening the child’s death.					
16- Treatment options for children with poor prognosis are discussed with the family in terms of the potential immediate and future impact on the child’s quality of life					
17- Allowing a terminally ill child who has DNR orders to die of an easily treatable problem such as pneumonia or low blood counts is the same as assisted suicide.					
18- Staff finds out what parents/families want for their child.					
19- Staff approach and offer emotional support to a family member who is openly					

grieving.					
20- The health care team assesses all sources of suffering of the family of the child with a life-threatening condition whether spiritual, emotional, psychosocial, or physical.					
21- Gtube/IV feedings are decreased or discontinued when a terminally ill child became congested or short of breath.					
22- It is a concern of the staff that a child is essentially being killed when unusually high doses of morphine or other opioids are given to treat a child’s pain.					
23- Caring for a dying child is so unpleasant that health care team members often try to avoid it.					
24- In my department, each child with a life-threatening condition has a designated individual, a physician or other health care provider, who is identified as responsible for coordinating the child’s overall care.					
25- It is helpful to the family for the staff to attend a child’s funeral.					

26- In my department, each child with a life-threatening condition has a written plan of care, which is documented and communicated across all care settings.					
27- Bereavement support offered and/or provided to families after the death of a child is inadequate.					
28- It is a general expectation that staff in my role (nurse) should be free to display emotions at the time of a child's death.					
29- There are sufficient opportunities for staff to offer emotional support to one another.					
30- Clinicians and parents generally agree about what constitutes medically futile					
31- The health care team assesses all sources of suffering of the child with a life-threatening condition, whether they are spiritual, emotional, psychosocial, or physical.					
32- It is appropriate for colleagues to console one another when a patient die.					

BARRIERS INVENTORY

41. To what extent do you perceive or have experienced the following issues as impeding your ability to care for children with life-threatening conditions and their families?

Items	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
41. Consistency and coordination of complex care among multiple providers					
42. Availability of pain and symptom management experts					
43. Patient/family psychological and/or emotional needs					
44. Patient/family spiritual needs					
45. Conflict with other professionals					
46. Reimbursement systems					
47. Amount of time required					
48. Lack of palliative care training					
49. Cultural views of the family					
50. Emotionally draining for the provider					

51. Limited experience with pediatric palliative care					
52. Parents disagree with treatment plan					
53. Comfort level in delivering bad news					
54. Caregiver belief that hospice and palliative care are separate from curative care					
55. Family belief that palliative care and hospice care are “giving up”					
56. Physician belief that palliative care and hospice care are “giving up”					
57. Fear of legal action by family					
58. Communication difficulties between staff and families					
59. Conflict among family members about treatment plan					
60. Staff shortages					
61. Availability of quality pediatric hospice programs					

مواقف ممرضين الأطفال وممارساتهم وحواجزهم تجاه الرعاية التلطيفية للأطفال وعائلاتهم .

إعداد: أثير ناصر حسين قشوع

المشرف: فريد اغريب

الملخص

مقدمة: الرعاية التلطيفية (PC) هي نهج يحسن نوعية حياة المرضى وأسرهم الذين يواجهون المشكلة المرتبطة بالأمراض التي تهدد الحياة ، وذلك من خلال الوقاية والتخفيف من المعاناة عن طريق التحديد المبكر لها ، التقييم المثالي ، علاج الألم وغيرها من المشاكل الجسدية والنفسية والاجتماعية الروحية.

لقد كانت الرعاية التلطيفية في السنوات السابقة معروفة برعاية المريض القريب من الموت ، ولكن الآن ، توسعت قدرة الرعاية التلطيفية لتشمل المرضى الذين قد يعيشون لسنوات طويلة والذين يعانون من مرض مزمن.

الهدف: هدفت هذه الدراسة إلى تقييم موقف واتجاه الممارسة والحواجز حول الرعاية التلطيفية بين الممرضات العاملين في أجنحة الأطفال في اثني عشرة مستشفى من المستشفيات الخاصة في الضفة الغربية ، فلسطين.

الطريقة : تم استخدام طريقة الدراسة الكمي والصفي لإجراء أخذ العينات الطبقية لإجراء الدراسة. تم تناول فرضيتين بحثيتين باستخدام عينات مستقلة t-test ، وباستخدام طريقة التحليل الإحصائي لـ ANOVA.

تم اختيار عينة من 236 ممرضة تعمل في جناح طب الأطفال في اثني عشرة مستشفى من المستشفيات الخاصة. ولقد تم جمع البيانات باستخدام الاستبيان مع البيانات الديموغرافية وبواسطة مسابقة الممرضات للعناية التلطيفية (PCQN) ، ومن اتجاهات ومواقف فرو ميلت نحو الرعاية لمقياس ما يسمى بالموت .(FATCOD) أجريت ايضا دراسة تجريبية بين 20 ممرضة.

النتيجة: توجد فروق ذات دلالة إحصائية بين اختبار الرعاية التلطيفية في درجات الممرضات على أساس النوع ($p = 0.030$) ومستوى التعليم ($p = 0.017$) في مجال تخفيف الألم وغيرها من الأعراض فقط.

وبالمثل أظهرت نتائج هذه الدراسة وجود فروق ذات دلالة إحصائية بين درجات استطلاع اتجاهات ومواقف الممرضات وفقا لعدد المسجلين في جميع المجالات الفرعية بما في ذلك: الرعاية الشاملة للطفل ($p <0.001$) ، دعم وحدة الأسرة ($p = 0.002$)) ، إشراك الطفل والأسرة في الاتصال ($p <0.001$) ، واستمرارية الرعاية ($P = 0.001$).

لم تكشف النتائج عن أي علاقة ذات دلالة مع المتغيرات الديموغرافية المحددة للحالة الوظيفية، الفئة العمرية ، التعليم ، مركز التمريض ، والخبرة السابقة في مجالات الرعاية الشاملة للطفل ، ودعم وحدة الأسرة ، وإشراك الطفل والأسرة في التواصل ، استمرارية الرعاية ، ودعم ومواساة أصحاب الأحزان والمصائب.

الخلاصة: كان لدى الممرضات معرفة ضعيفة في هذا المجال ، ولكن كان موقفهن تجاه الرعاية التلطيفية إيجابياً وملائما.

هذه الدراسة تقدم في نهاية المطاف الدعم لإدراج الرعاية التلطيفية في تعليم التمريض. وتكمن مسؤولية كلية التمريض الجامعية تجاه هذا المجال هو في التأكد من أن مناهجها يشمل ويعكس احتياجات الممارسة الحالية لهذا المجال. إن العلم والدراية حول الرعاية التلطيفية يساعد الممرضات على التغلب على العديد من العوائق الموثقة في إدارة الأزمات لدى المرضى المهددة حياتهم بالموت.

التوصيات : توصي الباحثة في دمج سياسة الصحة الوطنية المتعلقة بالرعاية التلطيفية في المناهج الدراسية الوطنية للتعليم في مجال التمريض وتوفير التدريب المناسب في مجال الرعاية التلطيفية للممرضات.