



Development of Pediatric Palliative Care globally

Caroline Awino Otuoma

Degree Thesis
Nursing Degree Programme
2019

DEGREE THESIS	
Arcada	
DegreeProgramme:	Nursing
Identificationnumber:	
Author:	Caroline Awino Otuoma
Title:	Development of Pediatric Palliative Care globally
Supervisor (Arcada):	Pauleen Mannevaara
Commissioned by:	
Abstract:	
<p>Palliative care improves the quality of life of patients living with life- threatening condition or life-limiting condition and families. With the growth of children with serious illness, need for palliative care around the world has increased tremendously, particularly in developing countries, where resources are limited. However, the development of pediatric palliative care has come with challenges that have hindered access to pediatric palliative care. This study explores development of pediatric palliative care globally and the challenges faced during the implementation of pediatric palliative care into healthcare system globally. Two research questions posed were: 1) How can Pediatric Palliative Care be developed globally? 2) What are the challenges to development of Pediatric Palliative Care globally? A literature review of the study was conducted to investigate the research questions. The inclusion criteria was used during the selection of the 12 articles, which were found to be relevant to the research questions. The following databases were used to search for the articles: PubMed, CINAHL, EBSCO, ScienceDirect and in Google scholar. Articles with one of the following keywords: Development of Pediatric Palliative Care globally, Challenges/barriers to development of Pediatric Palliative Care, integration of pediatric palliative care and implementation of pediatric palliative care were included. Paterson and Zderad's Humanistic Nursing Theory (HNT) was used to explain the nursing practices applied during the nursing process for children with Life-threatening condition or Life-Limiting condition and their families during Palliative Care. The findings revealed that effective communication was the major key to development of Pediatric Palliative Care. Through effective communication, quality of life of children with serious illness at the end of life and their families improved physically, emotional and spiritually. In the contrary, ineffective communication hindered the provision of Pediatric palliative care, thus impairing the quality of life of children with serious illness and their families.</p>	
Keywords:	Pediatric palliative care, effective communication, quality of life, life-limiting condition, life-threatening condition, end of life care
Numberof pages:	48
Language:	English
Date of acceptance:	

Table of Contents

1	Introduction	6
2	Background	8
2.1	Palliative Care	8
2.2	Pediatric Palliative Care	10
3	Theoretical framework.....	13
3.1	Metaparadigm concepts.....	13
3.1.1	<i>Person</i>	13
3.1.2	<i>Health</i>	14
3.1.3	<i>Environment</i>	15
3.1.4	<i>Nursing</i>	16
3.2	Summary	16
4	Aim and objectives of the study.....	18
4.1	The aim of the study.....	18
4.2	Research questions	18
5	Research methods	19
5.1	Literature review.....	19
5.2	Data collection.....	19
5.3	Inclusion and Exclusion criteria.....	19
5.4	List of chosen articles.....	21
5.5	Data analysis.....	22
5.5.1	<i>Reading and coding</i>	22
5.6	Research ethics.....	23
6	Results.....	24
6.1	Development of PPC globally	25
6.1.1	<i>Care providers related</i>	25
6.1.2	<i>Patient and family related</i>	27
6.1.3	<i>Organization related</i>	27
6.2	Challenges to development of PPC globally.....	29
6.2.1	<i>Care provider related</i>	29
6.2.2	<i>Patient and families related</i>	30
6.2.3	<i>Organizational related</i>	31
7	Discussion	32
7.1	Discussion of results related to conceptual framework of humanistic nursing theory	32

7.2	Discussion of results related to other literatures	35
8	conclusions	42
8.1	Recommendation	43
8.2	Strength and limitations of the study	44
	References	51

Figures

Figure 1. Palliative continuum care.....	10
Figure 2. Current Children Palliative Care globally.....	12

Tables

Table. 1. Categories of life-limiting and life-threatening conditions.....	13
Table 2: Search terms and search results on data collection and selection criteria.....	22
Table 3: Theme, categories and sub-categories used in the data analysis.....	26

1 INTRODUCTION

Approximately, 40 million people need of palliative care yearly, but only 14% of people in need of PC at the end of life currently receive it and 98% of children in need of palliative care are from Low and Medium Income Countries (LMICs). As a result, WHO and Members states were called upon to improve access to palliative care during World Health Assembly resolution WHA67.19 held in 2014. The care was to emphasize primary healthcare and community/home-based care mostly for oncology patients both children and adults in need of palliative care (WHO, 2019).

Pediatric Palliative Care (PPC) targets children and adolescents with life-threatening condition or life-limiting condition and their families. To provide the optimal quality of life, it is recommended that the care begins at diagnosis through the treatment to death and after bereavement. Access to pediatric palliative care is fundamental whether there is cure or not irrespective to country of origin. (Bergstraesser, 2013). Approach to Palliative care includes several components with the help of multidisciplinary team who come up to support patients and their families emotionally, spiritually, psychosocially and physically. The support is meant to help patients and their families fulfill their needs and goals as well as provide them comfort throughout the illness trajectory. Patients and families that receive palliative care on time are likely to avoid unnecessary hospital admissions. Palliative care can be provided in other locations such as homes, health centres and hospices other than hospitals (WHO, 2019).

Alleviation of pain and suffering especially for oncologic patients at the end of life care is necessary through administering medication. Proper pain and symptom management at the end of life care brings comfort and reduces distress as well as anxiety to children and their families, hence high quality of life. Unfortunately, not all children and families have access to this care, particularly those living in developing countries where access to resources are limited. For this reason, different organizations have come together to see that children and families that need Pediatric Palliative care gives access to different programs and services to children with life-limiting condition or life-threatening condition which improves the quality of life and care. With the implementation of Pediatric

Palliative Care (PPC) within the health care systems, quality of life and care of children and families is likely to improve tremendously (Rodriguez-Galindo et al, 2013).

In the introduction chapter, the researcher has briefly presented the concept of the study. The background chapter looks at the general aspect of palliative care and pediatric palliative care. In theoretical framework chapter, a nursing theory has been applied to discuss the study. The aim and objective chapter presents the aim of the research and the research questions used to investigate the study. The methodology chapter outlines the method of data collection that has been used. In the findings chapter, the researcher outlines the research outcome while in discussion chapter, findings of the study are discussed in detail. The last chapter consists of conclusion, recommendations and critical review. It looks at the conclusion drawn from the study, limitations and strength of the study as well as areas of improvement towards the development of pediatric palliative care.

2 BACKGROUND

As stated by International Children's Palliative Care Network (2015) in the principles of children's palliative care that palliative care can be over years depending on the time span of the child's illness, which may differ from the adults' time span. Anyone with life-threatening illness has a right to palliative care whether a child or adult as well as their families regardless of their country or region. Thus, International Children's Palliative Care Network (ICPN), due to increase in need of children's palliative care worldwide, is focusing into raising awareness of these needs, providing information exchange and encouraging the development of different palliative care models through children's palliative care professionals. ICPN, 2015 further explains that this form of network will allow increased lobbying in children's hospice and palliative care on the agendas of governments as well as inclusion in Non-governmental Organizations (NGO) development programs (ICPCN, 2015).

Pain and symptom management has been revealed to be one of the major components towards the approach of palliative care. The major reason being that most of the patients undergoing palliative care who are living with life limiting conditions such as cancer, tend to frequently suffer from pain and other serious symptoms such as anxiety, nausea, dyspnea among others. Therefore, need for proper medication to manage the pain and symptoms are recommended for patients in need of palliative care. On the other hand, it is part of an ethical responsibility to help alleviate suffering as well as adhere to the concept of dignity during caring of patients in need of palliative care. Use of opioid analgesics for pain management in connection to progressive conditions is essential (WHO, 2019).

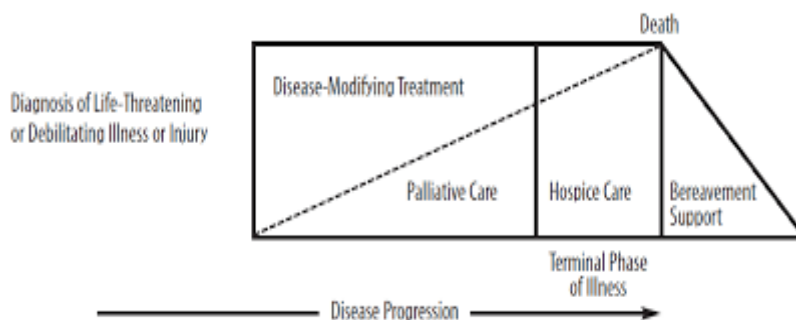
2.1 Palliative Care

Palliative care is an approach of care to improve the quality of life of patients, child or adult, and their families who are faced by challenges as a result of life-limiting or life-threatening condition. The approach involves prevention and alleviation of suffering with the help of multidisciplinary team. There have been difficulties in understanding the meaning and concept of Palliative Care (PC). As a result, introduction of the care

has been applied late during an illness which could have required an earlier PC approach despite being a child or an adult patient (Bergstraesser, 2013).

Previous studies by Cheng et al, (2018) quoted that the earlier and clear information about the diagnosis, prognosis and method of treatment is discussed with the patients and their family members, the earlier PC starts as well as referral to PPC service. Connor & Bermedo, (2014) and WHO,(2019 recommends that Palliative Care should begin immediately after the illness is diagnosed and should continue through death and into bereavement to enhance patients' quality of life (see fig 1). Unfortunately, Cheng et al (2018) reported that there have been delays with PC integration, particularly with oncology patients.

Figure1. Palliative care Continuum



Sources: National Quality Forum. A National Framework and Preferred Practices for Palliative and Hospital Care Quality: A Consensus Report. Washington. DC; 2006

Earlier detection to the need for Palliative Care is necessary in order to prevent long-term suffering of the patient and family members as well as provide high quality care. From the study, Cheng et al, (2018) mentioned that pediatric oncology patients got access to any of the Palliative Care services prior to death. Data revealed delays with PC discussion and Palliative Care initiation to be of great impact to early access to PC services. Even though there were efforts to encourage earlier initiation, many pediatric oncology patients lacked access to PC service, whilst those who did, receive it near the

end of life. Thus understanding the current state of Palliative Care (PC) timing is appropriate in alerting efforts to expand PC access, increase duration time of children benefiting from Palliative Care and improve support pediatric oncologists Cheng et al (2018). On the other hand, having knowledge of when the PC should be implemented makes it easier for the Pediatric Palliative Care programs, who wish to implement an integrated model of care, be aware of the circumstances of the family while trying to provide the needed services (Knapp and Contro, 2009).

Hospice care has also been included as part of Palliative Care. It is a free standing faculty care for patients who are on their last weeks of life and care is mostly delivered at home. It is the last phase of palliative approach to care where patients' treatment or cure for illness is terminated and new care providers are delegated. Hospice care may be started on the grounds that there have come sudden complications with illness in the course of treatment. Therefore, pain management through provision of adequate medication (opioid analgesics) is the major key to care. Alleviation of pain and suffering at this stage is important in order to avoid unnecessary suffering as much as possible (Duddecim, 2019). Figure 1 shows the palliative care continuum of care

2.2 Pediatric Palliative Care

WHO (2019) defines pediatric palliative care as a substantial care of child's body mind and soul as well as supporting the family members. The care should begin at diagnosis throughout till after bereavement regardless of treatment or not. During palliative care, children's physical, psychological and social status should be evaluated as well as use of available resources. Other definition of PPC exists from organizations such as American Academy of Pediatrics (AAP) and Institute of Medicine (IOM). According to these organizations, PPC is fundamental not only to the child patient, but also child's family, which includes patients' siblings, parents and extended family members (Knapp & Contro, 2009).

The aim of Pediatric Palliative Care (PPC) is to promote optimal quality of life and care for a child living with life-threatening condition or life-limiting condition and family members. Promoting high quality of life and care implies that families are given opportunity to make choices such as place of care, place of death and emotional and bereave-

ment support (Together for short life, 2019). Pediatric Palliative Care (PPC) is fundamental among children with chronic and/or life-limiting condition in improving their quality of life. Statistics shows 26% of global population to be of ages under 15 years with a rise of 40% in the Sub-Saharan Africa of children with life-threatening and life-limiting illnesses (Population Reference Bureau, 2017). Fig. 2 shows ICPCN’s estimated current levels of children’s Palliative care worldwide.

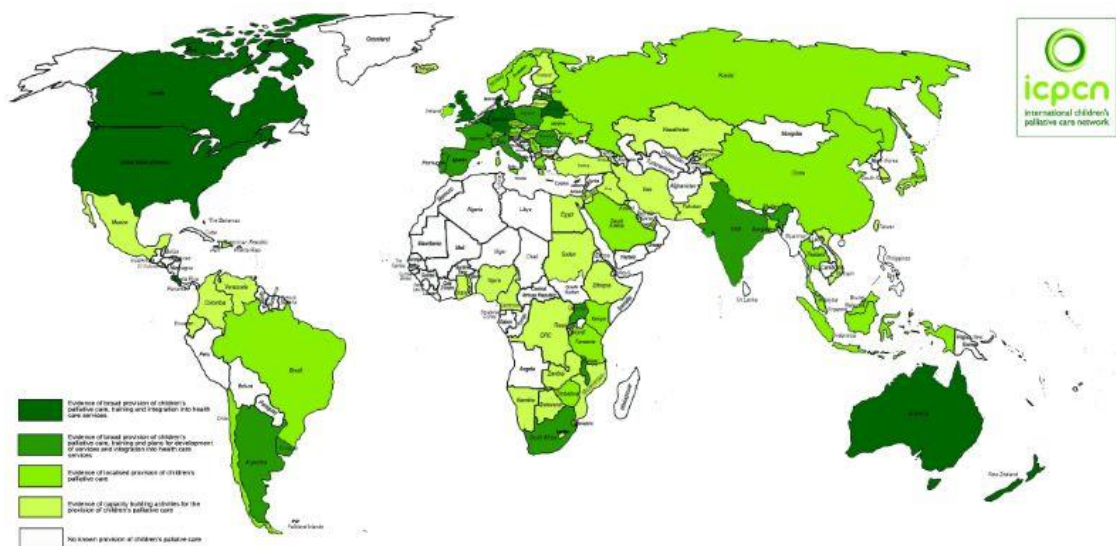


Fig.2 Current children’s Palliative Care globally. Darkest green represents extensive pediatric palliative care provision. Almost at full integration within health care services as well as a national policy to support Pediatric Palliative Care. Green represents extensive pediatric palliative care provision with training available and focused plans for development of services and integration into health care services. Medium green represents provision of localized Pediatric palliative care and availability of training. Lightest green represents capacity building activities for the provision of pediatric palliative care. White represents unspecified provision of pediatric palliative care (ICPCN, 2015).

Together for short life (2019) has classified four categories defining life-threatening and life-limiting conditions in childhood that would benefit from Pediatric Palliative Care service provision as illustrated in table 1.

Table 1 Categories of life-limiting and life-threatening conditions (Together for short life, 2019).

Category 1	Those children with life-threatening conditions for which curative treatment may be possible but can fail such as cancer, irreversible organ failures of heart, liver, kidney
Category 2	Those children encountering long periods of intensive treatment aimed at prolonging Conditions, though chances of premature death are possible such as cystic fibrosis, duchenne muscular dystrophy.
Category 3	Those Children with progressive conditions without treatment such as batten disease, mucopolysaccharidoses
Category 4	Those Children having conditions with severe neurological disability which is not progressive, but are unpredictable.

3 THEORETICAL FRAMEWORK

Pediatric Palliative Care focuses on promoting high quality of life and care of children living with Life-Threatening Condition or Life-Limiting Condition and their families. Provision of optimum quality of care requires collaboration of multidisciplinary team who are to assess, evaluate and alleviate physical, psychological and spiritual distress of children and families (WHO, 2019). In order to fulfill these objectives to attain a high quality care, a nurse-patient relationship is necessary. Thus, the researcher decided to use Paterson and Zderad's Humanistic Nursing Theory (HNT), through the Metaparadigm Concepts, to explain the nursing practices applied during the nursing process while caring for children with Life-threatening conditions (LTCs) or Life-Limiting conditions (LLCs) and their families during Palliative Care (PC). The theory states that there has to be a dialogue or an interaction between a nurse and a patient for a nurse-patient relationship to build up. Therefore, a nurse by using his/ her own experience modifies her response by offering to be present when the patient calls for help. For this reason, Paterson and Zderad termed this process as a “reciprocal call and response”, while Franca et al, (2018) quoted the theory to be “dialogical in its theoretical and practical aspects”. Both humanism and existentialism has been applied to the nursing theory. Humanism, in that, an individual should be understood from his/her own experience, while existentialism to emphasize an individual’s uniqueness and ability to make informed choices.

3.1 Metaparadigm concepts

3.1.1 Person

According to Humanistic Theory of Paterson and Zderad, human beings have special life experiences. They should be valued, respected, nurtured and understood when making decisions concerning their health, which may include families and communities. Thus, through the guidance of HNT, humanism during caring for a child living with chronic condition (CC) or Life Limiting Condition is inevitable. Taking care of children and their families’ special needs as well as psychological, emotional, spiritual and physical well being adheres and responds to the theory (Franca et al, 2016 and Franca et al,

2018). Franca et al, (2016) and Coad et al, (2014) suggested that participation of children in important decision making about their treatment should be respected. The authors reasoned that encouraging the involvement provides the children and their families with a clear care plan about the process of treatment. In addition, nurses will have promoted the humanized care by respecting the uniqueness of the child patient through honesty and open talk, which will have improved the quality of life and care.

3.1.2 Health

Nursing has been defined as a *nurturing response* of one person (nurse) to another (patient) in a time of need that aims towards the development of *well-being* and *more-being*. It is also related to the state of a person's healthiness or illness, in other words, the health-illness quality of the human condition. Paterson and Zderad further explained that not only is nursing dealing with matters of life and death, but also the quality of a person's living and dying. Even though health has been understood by many to mean absence of a disease, the same goal does not apply to children diagnosed with Chronic Condition or Life-Limiting Condition as well as terminal patients. Nevertheless, their condition still calls for provision of nursing care throughout the illness trajectory regardless of treatment. In this case, Nursing, as a human response, should value human potential beyond the concept of health as an absence of disease (Paterson and Zderad:Humanistic Theory).

This has been reflected in a study by Franca et al, (2018), whereby the application of HNT in the practice of PC in the pediatric oncology guides and perfects nursing practice in an existential way for children with Life Limiting Condition (LLC). Suffering from LLC such as cancer places children and families in a distressful situation leading to stressful experiences such as anxiety, emotions just to mention a few. This brings fear knowing that they have limited time as day gets closer. Therefore, living with an incurable disease needs provision of care to alleviate pain and suffering that will help the children live a comfortable life towards the end of life, through provision of Palliative Care (Franca et al, 2018).

3.1.3 Environment

Paterson and Zderad defines environment as “the place where the service is delivered, the community or the worlds”. They further clarified that, “it is the time and space where nursing experience takes place”. Therefore, the presence of experience in context of time is important in order to understand nursing dialogue. The space where the interaction takes place between the patient and nurse matters. It should be an area of motivation where the patient feels comfortable and secured to freely interact without fear (Paterson and Zderad). This existential perspective of time and space as lived by children and families during end-of-life care supports the Humanistic Nursing. Nurses’ existential awareness of children and families, hence need for transactional relationship (Paterson and Zderad: Humanistic Theory).

Franca et al, (2018) mentioned in their study that children and families, according to WHO, have right to PC from diagnosis to bereavement and that their dignity and autonomy will be preserved. Humanist nursing is noticed during this time of experience, when nurses’ presence, either by the bed side in the hospital or patients’ home, to support and show empathy to the children and families at the end-of-life care is applied. Children and families have the right to choose a suitable environment where they can find comfort, especially at the end-of-life care. Several options are always available such as hospitals-based, hospice homes or home-based, depending on the needs and goals of the children and families. Most children and families tend to prefer home settings rather than hospitals, where they could enjoy being close to their loved as they spend last peaceful moments of their life.

Crozier and Hancock, (2012) mentioned that even though communication is one of the major components in improving the quality of life children and their families, use of right words is important to make communication effective. Thus, a moment of silence while listening during an interaction between the nurse and children and families (I-US) during therapeutic conversation is important depending on the time and space.

3.1.4 Nursing

Nursing has been defined by Paterson and Zderad as ‘lived experience between human beings’. Nursing is viewed as a transaction between human beings (patient and nurse). Through nursing, human situation is being responded when he/she calls (Paterson and Zderad: Humanistic Theory).

Proper interaction through dialogue requires effective communication for trust between a nurse and a patient. Coad et al, 2014 and Crozier & Hancock, (2012) mentioned that children and families depend on good communication skills from health care providers to help relate on matters concerning diagnosis, treatment goals and Palliative Care services among others. With communication barrier in the course of Pediatric Palliative Care (PPC), there would arise misunderstanding of diagnosis, inadequate provision of emotional support and delay in the referral to palliative care just to mention a few. As a result, the quality of care and life of the pediatric and families will be hindered. This will also slow down the transaction between nurse and children and families hence lack of response when in need of help. Finally, the existential suffering and pain particularly of pediatric at end-of-life care will have not been attended to.

3.2 Summary

Humanistic Nursing Theory is important in Pediatric Palliative Care, particularly during Pediatric End-of-life-care. By being there and doing with the children and families during PC, creates a Humanistic Nursing approach. The presence of healthcare providers to improve the quality of life of children and families by alleviating pain and suffering in the course of the illness trajectory is relevant. The nurse-patient relationship at this point is necessary as it creates trust which later on improves the interaction process hence the nursing process. A nurse responding to the call and being present to apply his/her experience, nurtures well-being and more-being (Paterson and Zderad: Humanistic Theory).

Franca et al, (2016) mentioned that the availability of a nurse to improve the quality of life of a child with incurable disease is important. The authors further mentioned that based on Humanistic Nursing Theory, inter-subjective transaction enables a child to

share feelings, emotions, pain and suffering with the nurse. This enables the nurse to be present to care for the child and his/her families' well-being and being better. Humanistic Nursing is also important in provision of dignity and comfort when children and families are in a position to participate in the decision-making of their treatment. On the other hand, it enables a nurse to respect the children and families by understanding their uniqueness as humans in the course of transaction.

4 AIM AND OBJECTIVES OF THE STUDY

4.1 The aim of the study

Need for PPC service globally is growing fast. However, access to the service is limited in many parts of the world. Data collected from previous studies through literature review revealed a big percentage of children and their families needed access to PC with some in need of specialist services. Estimation done by ICPCN, (2015) on the level of pediatric palliative care provision globally revealed that there has been limited access to PPC services, particularly in resource poor countries. The aim of this study is to investigate the development of PPC globally.

4.2 Research questions

In order to meet the aims the following questions were addressed:

1. How can Pediatric Palliative Care be developed globally?
2. What are the challenges to development of Pediatric Palliative Care globally?

5 RESEARCH METHODS

5.1 Literature review

The researcher used a literature review to conduct the study to investigate the development of Pediatric Palliative Care globally. Through literature review, researcher was able to compare previous findings as well as critique existing findings, which needed further studies. Search of the articles was conducted through electronic sources such as electronic database and Google scholar.

5.2 Data collection

To investigate the challenges to development of Pediatric Palliative Care globally, particularly in resource poor countries, a literature review was used to conduct this study and identify strategies to overcome them. Due to ethical issues and time consumption, interview was seen not to be preference as the best method of collecting data to investigate this study. To access more recent and relevant data on development of Pediatric Palliative Care (PPC) and the challenges encountered, several databases were utilized to search for information. Data retrieval was done in Google scholar and Arcada's databases which included CINAHL, Academic Search Elite (EBSCO), PubMed and Science Direct. The key words used were: Pediatric palliative care, Development of pediatric palliative care globally, Integration of pediatric palliative care, Implementation of pediatric palliative care, Challenges to development of pediatric palliative care and Barriers to development of pediatric palliative care.

5.3 Inclusion and Exclusion criteria

Inclusion criteria was based on the relevancy from the title and abstract of the articles and if they were in English and published not later than 2009. Articles that were relevant to the research questions and had two or more key words: were included. The term 'Hospice care' and 'end of life care' were included in the search because they are part of palliative care continuum. Advanced search was used during the search of the articles using Boolean search phrase. The search was limited to peer-reviewed, free full text and

systematic reviewed articles. After exclusion and inclusion criteria from 82 articles retrieved from all 4 databases, a total number of 12 articles which were relevant to research questions were finally chosen. Table 2 below illustrates the processes of data collection and selection criteria.

Table 2: Search terms and search results on data collection and selection criteria

No.	Boolean search phrase	CINAHL	EBSCO	Pub Med	ScienceDirect
1.	Pediatric OR children OR adolescent AND palliative care OR hospice care OR end of life care AND development	27	107	90	220
2.	Pediatric OR children OR adolescent AND palliative care OR hospice care OR end of life care	165	151	307	91
3.	Challenges OR barriers AND Pediatric OR children OR adolescent AND pallia- tive care OR hospice care OR end of life care AND development	4	12	21	45
	After exclusion and inclusion criteria	14	16	35	17
	Final articles chosen from the inclu- sion and exclusion criteria mostly rel- evant to the research questions	1	1	7	3

5.4 List of chosen articles

The following 12 articles were chosen based on the inclusion and exclusion criteria shown in the table above as well as relevant to the research questions.

1. Hawley, P. (2017). 'Barriers to Access to Palliative Care', *Palliative care*, Vol. 10
2. Benini, F., Orzalesi, M., Santi, A., Congedi, S., Lazzarin, P., Pellegatta, Zen, L.D., Spizzichino, M. & Alleva, E. (2016). 'Barriers to the development of pediatric palliative care in Italy', *Ann Ist Super Sanità*, Vol. 52(4), pp. 558-564.
3. Neha, C. & Vivek, K. (2016). 'Challenges to Palliative Care in Pediatric Patients', *Journal of Palliative Care & Medicine*, Vol. 6(3).
4. Blazin, L. J., Cecchini, C., Habashy, C., Kaye, E. C. & Baker, J. N. (2018). 'Communicating Effectively in Pediatric Cancer Care: Translating Evidence into Practice', *Children (Basel, Switzerland)*, Vol. 5(3), 40.
5. Friedrichsdorf, S. J. & Bruera, E. (2018). 'Delivering Pediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliative', *Children (Basel, Switzerland)*, Vol. 5(9), 120.
6. Muñoz-Blanco, S., Raisanen, J. C., Donohue, P. K. & Boss, R. D. (2017). 'Enhancing Pediatric Palliative Care for Latino Children and Their Families: A Review of the Literature and Recommendations for Research and Practice in the United States', *Children (Basel, Switzerland)*, Vol. 5(1), 2.
7. Khraisat, O. M., Alakour, N. A. & O'Neill, T. M. (2017). 'Pediatric End-of-life Care Barriers and Facilitators: Perception of Nursing Professionals in Jordan', *Indian journal of palliative care*, Vol. 23(2), 199-206.
8. Downing, J., Boucher, S., Daniels, A. & Nkosi, B. (2018). 'Paediatric palliative care in resource-poor countries', *Children (Basel, Switzerland)*, Vol. 5(2), 27.
9. Weaver, M. S., Heinze, K. E., Bell, C. J., Wiener, L., Garee, A. M., Kelly, K. P., Casey, R.L., Watson, A. & Hinds, P.S. (2015). 'Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review', *Palliative medicine*, Vol. 30(3), 212–223.
10. Doherty, M. & Thabet, C. (2018). 'Development and Implementation of a Pediatric Palliative Care Program in a Developing Country', *Frontiers in public health*, Vol.6, 106.

11. Hui, D. & Bruera, E. (2015). 'Integrating palliative care into the trajectory of cancer care.', *Nature reviews. Clinical oncology*, Vol. 13(3), 159-71.
12. Kaye, E.C., Rubenstein, J., Levin, D., Baker, J.N., Dabbs, D. & Friebert, S.E. (2015). 'Pediatric Palliative Care in the Community', *A Cancer Journal for Clinicians*, Vol. 65(4), pp. 315-33.

5.5 Data analysis

A content of analysis was used to analyse 12 articles as a base of categorization through Granheim & Lundman's (2004) qualitative approach. The authors outlined two principle uses of content analysis as quantitative and qualitative approaches. The researcher used a qualitative approach because the study was based on a nursing research. Therefore, the analysis was done through a process of classification, evaluation and verification of qualitative data.

The authors expressed the meaning of manifest as 'what the text say' while latent as 'what the text is talking about'. The unit of analysis consists of words or phrases in a text to be read and reviewed before analyzing a data. Meaning units are words, sentences or paragraphs that relate to each other in form of content and context. A code represents the labels of the meaning unit. The authors explained that using a code to label a meaning unit brings new and different way of thinking about a data. In the contrast, the understanding of the code should be related to the context. These codes are then joined to form categories. Categories are descriptive meaning, they answer the question 'what'. In addition, a category can further be divided into sub-categories. Theme is an underlying meaning on an interpretation level consisting of condensed meaning units, codes or categories.

5.5.1 Reading and coding

The researcher went through each article repeatedly at the same time making notes in the margins on relevant information connecting to the research question. During this process, the meaning units were marked and labeled using codes. The codes were related to the keywords, which were highlighted using a luminous green colored marker.

This was done for easy identification during the reading process. Later on the codes were categorized relevant to research question. The categories were further divided into sub-categories.

5.6 Research ethics

Zietman, (2013) has outlined the major form of research misconduct as defined by The Committee on Publication Ethics (TCPE) as fabrication, falsification and plagiarism. Thus, the researcher adhered to the principals of research ethics and avoided the above mentioned research misconducts when conducting this research study using literature review. The data collection was majorly from other secondary sources (scientific articles), therefore, the researcher followed the research ethics by ensuring that the sources used during the study were properly cited and referenced. In addition, texts from the sources were well paraphrased to ensure that they were not copy paste piece of work.

During the analyzing of data, there was no misinterpretation, changing or omission of important information through application of personal opinions besides the findings from the data collected. The researcher also ensured that the copyright rules were not violated by using sources from databases and articles which had open access. Due to researcher's pre-understanding of the phenomena through previous experience, bias of own experience that may have affected the interpretation of the results were eliminated. This was to enhance good quality production through the concept of reliability and validity as well as trustworthiness of the study.

6 RESULTS

The results presented below were based on the findings from the chosen articles. The findings from both research questions were more or less similar to each other with little differentiation. The numbers represented the chosen articles which were identified in the research method for analyzing data.

Table 3: Theme, categories and sub-categories used in the data analysis

Theme	Development of PPC globally			Challenges to development of PPC globally		
Major categories	Care providers related	Patient & family related	Organizational related	Care providers related	Patient & family related	Organizational related
Minor categories	communication, treatment and medication, training and education, Palliative, Palliphobia, Eligibility or referral criteria	Communication, decision-making, myths and beliefs, misconceptions	PPC services, Resources, infrastructures, Policies & guidelines, Awareness, Advocacy, Palliative, Pallialia	Reluctance to referral, communication, training and education, treatment and medication, resources, denial, Palliphobia	cultural beliefs, myths, religion, discrimination, socio economic status, misconceptions	PPC services, Resources, Infrastructures, Policies & guidelines, Awareness, Advocacy, Pallialia
Unit of analysis	1,3,4,5,7,8,9,11,12	1,3,4,7,8,9,10,11,12	1,3,4,5,7,8,9,10,11,12	1,2,3,6,7,8,9,10,11,12	1,2,3,5,6,7,8,9,12	1,2,3,5,6,7,8,9,11,12

6.1 Development of PPC globally

The findings were from the research of the chosen articles during the analyzing of data. The findings revealed a number of strategies that could be applied to enhance development of Pediatric Palliative Care (PPC) globally, particularly in resource poor countries. These strategies were categorized in relation to Care providers, Patient and family and Organization.

6.1.1 Care providers related

The findings highlighted in this section identified effective communication as the major key to integration of Pediatric Palliative Care (PPC) globally (4, 7, 9, 11). Empathic communication was noted to encompass physical, psychosocial and spiritual needs of children at the End of Life (EOL) care and their families (4, 12). Thus, excellent communication was emphasized during disclosure of diagnosis, addressing the effect of the illness and treatment or cure, end of life and after bereavement and establishment of therapeutic alliance. Involving a patient, siblings and extended-family members in communication about the prognosis was recommended (4). Effective communication was necessary during the establishment of therapeutic alliance at the end of life care of a disease in a refractory, progressive or relapsed stage. The authors suggested that establishment of therapeutic alliance at this phase through effective communication among patient, family and interdisciplinary would strengthen the bond and trust, thus, provision of optimal quality care during the End of Life (EOL) care (4). Support through interdisciplinary team consisting of physicians, nurses, advance practice clinicians, social workers, chaplains, child life specialists and psychosocial support staff was noted to improve the spiritual, emotional, physical and spiritual needs of children with serious illness and their families. Their teamwork and collaboration through effective communication was necessary for the continuity of care in the course of illness trajectory, particularly during pediatric end of life care (4, 12).

Rephrasing “palliative care” to “supportive care” by the pediatric oncologists was noted to reduce the level of stigma which was connected to PPC (1, 5, 9,11,12). A study by Friedrichsdorf et al, (2018) stressed that rephrasing palliative care to mean “Supporting”

implied that children and families had the possibility to live a life free from pain and suffering, but not help them die. On the contrary, in a case of an incurable disease, whereby a child was at a terminal phase, EOL care was provided to help the child die peacefully. Although a study by Hawley, (2017) noted that combination of either supportive care or palliative care with additional terms such as pain and symptom management was likely to fade the role of palliative care, thus hindering the fulfillment of patients' needs by the care team.

Early referral to palliative care for patient with advanced-stage of cancer was noted to optimize the survival, reduce aggressive treatments, distressing symptoms as well as improve prognostic awareness (5,11). Unfortunately, most healthcare providers were noted to be on denial about the implementation of pediatric palliative care services, which is necessary for children with Life-Limiting Condition (LLC) and families undergoing physical and emotional distress. The reason was lack of proper documentation on the need for symptom and pain management. Parent's participation on documentation through taking short video clips or testaments was suggested to help overcome the denial experienced by care providers (5). On the other hand, there was a question of who, when and how to refer patients with serious illness and families to palliative care (11,12).

Formal Palliative Care (PC) education and training for healthcare providers was necessary for provision of optimal quality care (1,3,8,10,11). The training enabled the care providers communicate effectively, manage pain and symptoms, and disclose diagnosis among others. Additionally, there was emphasis on basic palliative care training sessions for healthcare provider trainees who are on practical training as well as introduction of Palliative Care (PC) in medical and nursing school curricula to enable the students familiarize themselves with PC (10). It was suggested in a study by Doherty & Thabet, (2018) that already trained PC specialists in the field were to mentor and teach healthcare providers involved in caring for patients with serious illness. In order to shift Pediatric Palliative Care (PPC) to the next level of development, there was recommendation to design an administrative structure in resemblance to other departments such as oncology and infection. Findings mentioned the beneficial in continuation of medical education for oncologists in order to improve their level of proficiency in palliative care.

Thus, need for development of several training curriculum for oncologists to fill the gap. This was seen to be possible through different formats such as online programs, workshops and seminars (10,11).

6.1.2 Patient and family related

Parents advocating for their ill children through open end discussion about the diagnosis, prognostic and treatment were observed to improve the quality of life and care of their children. Involving children, particularly adolescents in decision-making concerning their treatment (3) was a way to adhere and respect ethical issues and norms (2) as well as an opportunity to get them open up and speak out their thought and fear concerning the illness (4). However, it was noted that parents ended up keeping some information from their children due fear of triggering anxiety or distress to them (4). Acceptance of a child's death when there was no cure, for example, at the end of life care of a disease in a refractory, progressive or relapsed stage, affected most parents. Findings from a study by Khraisat et al (2018) noted that acceptance of imminent death of a child by parents and family members would set a good example to other families, thus accept the end of life care sooner enough to avoid pain and suffering of their children. Involving patient and his/her family in family-centered advanced care planning after accepting a child's imminent death would help them make wishes regarding End of Life (EOL)care thus improving the quality of care (1,4,5,9,12).

6.1.3 Organization related

Advocacy was mentioned to be the key fundamental to development of PPC within all healthcare systems, particularly in developing countries. The research study further revealed that provision of enough knowledge and information about palliative care to healthcare providers would bring awareness of what it entails to children with serious illnesses and families in need of the services(6). It as well eliminated the erroneous understanding and misinterpretation of Pediatric Palliative Care to mean end of life or death (1,8,10). Implementation of Pediatric Palliative Care Programs was observed to contribute to the provision of optimal quality of care, particularly for children with serious illnesses at the End of Life phase and their families (3,8,9,10,11,12). However, a

study revealed that children and families living in resource poor countries were most affected compared to those living in developed countries due to inadequacy of these models of care (8).

A study noted that adequate workforce of trained interdisciplinary team was fundamental towards provision of Pediatric palliative care for children living with life-limiting condition or life-threatening condition and their families (1,12). Provision of palliative care for patients living with chronic illnesses was scarce compared to those with life limiting illness such as cancer. Access to specialist palliative care programs was observed to be limited in community hospitals and rural areas. Insufficient skills and knowledge by the healthcare professionals to enable them provide basic palliative care was noted lacking compared to the oncology section (1).

The findings from a study emphasized on the collection of evidence based data through research to enable recognition of Pediatric Palliative Care (PPC) urgency in different countries (8). Collecting data of the symptoms children with serious illnesses were having as well as measuring the rate of pain, advocated for the need of PPC services (8,5,10). On the other hand, findings from a research study by Hui and Bruera, (2015) recommended researchers to conduct well-designed clinical studies using questionnaires in relation to integration of palliative care to promote the integration of oncology and palliative care (11).

The study emphasized the reimbursement of concurrent care whereby provision of curative/prolonging therapies and PC services would operate side by side for children living with LLCs (1,5,12). Unfortunately, there was a mention of limitations with Concurrent Care Children application, particularly children living in the US with life-threatening illness and eligible for programs such as Medicaid or the State Children's Health Insurance Program. To fulfill this criteria, children with life-threatening illness and their families were to present a document anticipating child's death in the course of 6 months to enable them acquire hospice services (12).

6.2 Challenges to development of PPC globally

The results were from the research of the chosen articles during the analyzing of data. The findings revealed several barriers that have impeded the development of PPC globally, particularly in resource poor countries. These challenges were categorized in relation to Care providers, Patient and family and Organization.

6.2.1 Care provider related

The study revealed that insufficient communication was the major impact to development of PPC globally. Provision of high quality care to patients living with life limiting condition or life threatening condition and their families demanded an effective communication (3,6,12). This was found to be a deficit due to several factors such as inadequate training and education about palliative care for healthcare providers (3), cultural incompetency (4,12) and lack of trust and relationship between healthcare providers and patient and families(4,12) among others. The study emphasized that effective communication should started immediately when an illness has been diagnosed and should proceed throughout the treatment process till death and after bereavement (4). However, reluctance to referral of eligible patients for Pediatric Palliative Care (PPC) by physicians was observed in several studies. Several reasons behind the reluctance were outlined as lack of skills and knowledge about PPC, uncertainty of prognosis, assumption that the family might deny the referral, unawareness of PC and acceptance by the physicians that the treatment has failed and that they are not competent enough (1,10)

The number of trained care providers was noted to be limited, particularly in resource limited countries. This hindered the provision of optimal quality care especially with pain and symptom management during pediatric end of life care (8). In the contrary, limitations to delivery of opioids during pain and symptom management was observed in several studies and lack of trained medical healthcare providers was one of the reasons (1,2,3,5,8,12).The Finding was supported by Hawley,(2018) that healthcare providers working in community and rural areas were not well trained enough to provide basic Palliative Care (PC) services to the patients and families compared to those in oncology department.

Lack of treatment and medication impeded the provision of PC services to children with serious illnesses and their families. Medications such as morphine used for pain and symptom management was noted to be unavailable in Low and Medium Income Countries (LMICs) due to the high cost. However, even though available, opiophobia hindered the administering due to multiple beliefs. Nevertheless, access to these essential medications such as morphine were noted to be limited, thus Lancet Commission report focused on making sure that the medications were available and at affordable price. An essential package inclusive of medications was recommended by Lancet report, though it seemed to be a problem in some areas. Findings from the study mentioned that the medications were available for adults, but not yet accessible for children. Therefore, there have been efforts to enable the access of medication available to all children in need of them despite of their origin (8).

6.2.2 Patient and family related

There was reluctance with referral for PC consultations as well as specialist by some patients suffering serious illness such as cancer and their parents. The patients and families understood being referred to PC specialists meant death resulting to delay in provision of PPC services.

Due to age factor, ethical issues were mentioned to be difficult to adhere to especially during decision-making concerning child's treatment. However, parents had an opportunity to advocate for their children who were not in a position to make decision concerning their medical treatment (2). Though difficulties were noted after receiving information about child's diagnosis, which affected communication during decision-making due to distressful state children and their families were in. Apart from decision making after the disclosure of the diagnosis, cultural beliefs of some patients with chronic illnesses and families that use of medicine is a guarantee for cure of all kind of diseases, was observed to be a challenge to implementation of Pediatric Palliative Care (2,4,12). Cultural beliefs was further noted from a study by Munoz-Blanco et al (2017) to influence the provision of PPC for Latino children with serious illnesses and families that needed it. Additionally, several barriers such as poverty, traditional social support and healthcare system were observed to be hindrance to palliative care experience by the Latino children and their families.

6.2.3 Organizational related

Lack of resources such as Palliative Care (PC) units in developing countries, particularly for those children with chronic illnesses, was observed to be a challenge as well as access to specialist PC program (1,3). The rapid increase of children in need of PC was noted to have increased, thus, difficulty in providing trained healthcare providers and Palliative Care (PC) services without presentation of evidence based data (2). Limited access to health insurance due to lowest rates of insurance coverage was experienced by Latino children with chronic illness compared to other races/ethnic groups who also had children with chronic illnesses. Additionally, discrimination due to their race and economical status limited them to access to PPC services (6).

Policies and guidelines to provision of pediatric palliative care services were noted to vary in different countries. For example in resource poor countries, PPC services for patients with Human Immune Virus (HIV) and Non Communicable Diseases were excluded. Findings from the authors' study mentioned that the funds were limited and the number of donors had decreased tremendously over the past year (8). Unawareness about PPC services by pediatricians and other interdisciplinary team was noted, thus, inadequate knowledge and competence to provision of PPC (1,).

7 DISCUSSION

The discussion of the results was based on conceptual framework of humanistic nursing theory and literature from the chosen articles.

7.1 Discussion of results related to conceptual framework of humanistic nursing theory

Paterson and Zderad's Humanistic Nursing Theory expresses the importance of human relationship in the course of performing a nursing practice. The authors used four meta-paradigm concepts: person, health, environment and nursing to explain their connection with nursing practice. Thus, the discussion of the results will be focusing on the four concepts during caring of patients and families undergoing palliative care in order to improve their quality of life and care.

Humanistic Nursing (HN) involves conversation through a dialogue between two human beings. In this case, a patient and his/her family interact with the healthcare providers with an objective of improving the quality of life and care. Since palliative care begins at diagnosis throughout the illness trajectory, same applies to communication when physician discloses information about diagnosis, prognostic and treatment. In the process of interaction, Blazin et al, (2018) & Kaye et al, (2015) stated that effective communication is essential to assist children and their families in decision-making about the future choices and goals as well as early referral to palliative care. As a result, there will be recognition for dignity and high quality care. On the other hand, during provision of integral and humanized care, efficient communication enables healthcare providers to empathically recognize patients and their families as well as embrace their needs.

In Humanistic Nursing approach, interaction through dialogue requires effective communication for establishing and development of trust and bond between the care providers, children living with LTCs or LLCs and their families. To enable children and families participate in conversation about their goals and needs during pediatric care, especially end of life care, trust must have developed , which will have promoted the quality

of life and care during the illness trajectory. On the contrary, effective communication is not only meant for building up trust and relationship among the care providers, patients with life threatening illness and families, but also the entire interdisciplinary team (Kaye et al, 2015). For example, during the disclosure of information, mutual understanding, opinion and agreement concerning the diagnosis, prognostic as well as treatment among different physicians is noted to avoid the delay to referral and provision of Palliative Care. Therefore, to provide an optimal quality care, physicians are encouraged to come into equal understanding and decision regarding patients diagnosis, in order to avoid the delay since it was noticed to have impact on the quality of life of a child with serious illness and hi/her family (Kaye et al, 2015).

Collaboration and teamwork among the healthcare providers during the process of care provision for children with serious illness and families requires efficient communication. Additionally, it decreases anxiety and gives hope to children with serious illness and families in the course of treatment, hence improves quality of life. Healthcare providers involving themselves in communication with the families after child's death speeded up the healing process during grieving period. In addition, the bonding between parents and healthcare providers should be maintained as part of their grieving period. This aspect was mentioned to help erase the feeling of abandonment experienced by parents when care providers ceased communicating after the death of their children of which was partly noted to result to long period of grieving (Blazin et al, 2018).

Availability of Pediatric Palliative Care (PPC) programs for children living with Life-limiting or Life-threatening condition promotes optimal care and improves quality of life. These programs provide them with places where services and care could be delivered. Children with life limiting condition such as cancer and families have a right to choose a comfortable and safer environment suitable for them to receive care and service at the end of life phase. Care location as desired by children and families at end of life care should be respected by the pediatric palliative care team (Kaye et al, 2015). This existential perspective of time and space as lived by children and family members during end of life care fulfils the humanistic nursing care. During this time of experience, care providers' presence is highly recommended and being by the bedside as well as giving support to the family members physically, emotionally and spiritually (Khra-

isat et al, 2018 & Kaye et al, 2015). At this stage of illness, pain and symptom management is fundamental, thus the presence of pediatric palliative care team to assure that these children and their families are provided with optimal care and comfort is necessary. At this stage of care, proper administering of medication to prevent pain and symptoms such as nausea, dyspnea, vomiting among others is evident.

Nursing deals with both matters of health and death as well as the quality of a person's living and dying (Paterson and Zderad: Humanistic Nursing). Pediatric Palliative Care (PPC) aims at improving the quality of life of children with life-limiting condition or life-threatening condition and their families. It demands multidisciplinary team consisting of physicians, nurses, advance practice clinicians, social workers, chaplains, child life specialists and psychosocial support staff physicians to provide high quality care. This care team should be highly skilled and capable of providing different pediatric palliative care services, which would promote optimal quality of life of children with serious illness and their family members. Thus, formal training and education is fundamental. With proper training and education on Palliative Care, the care providers will have attained high level of knowledge and adequate skills on how to communicate with patient during the End of life care, manage pain and symptom and handle general palliative care (Neha and Vivek , 2016, Blazin et al, 2018,Hui and Bruera, 2015 & Kaye et al, 2018). Adequate knowledge on pain and symptom management, being one of the major components of palliative care enabled the care team administer appropriate medication and treatment which would bring comfort to a child patient and his/her families. The administering of medication through different routes such as interdermal, parenteral or rectal helps children who find oral route challenging. For example, during distressful symptoms such as nausea and vomiting, other means of administering medication is advisable.

Health having been understood by many to mean that there is absence of disease or illness, does not imply with children suffering from chronic condition or on terminal care. On the other hand, World Health Organization 's (WHO) principle states that a patient has a right to palliative care whether there is no cure or treatment. Provision of high quality care through provision of medication to prevent pain and symptoms, awareness of palliative care as well as treatment by a group multidisciplinary team will still be

necessary for this group of patients to improve their quality of life and care. Therefore, in humanistic, concern for nursing does not point only a person's well-being, but also more-being (Paterson and Zderad: Humanistic Nursing).

Human beings have special life experiences, therefore they are to be valued, respected, nurtured and understood with the right to make decision concerning their health. Therefore, involving adolescents in decision-making about their medical treatment is a way to adhere to the autonomy and respect their dignity. On the other hand, their participation encourages them to open up and share thoughts about their feelings towards treatment and illness (Blazin et al, 2018)

7.2 Discussion of results related to other literatures

Development of Pediatric Palliative Care (PPC) globally can be effective through utilization of variety strategies by care providers, patients and families and organizations in order to improve the quality of life and care in the course of illness trajectory. On the contrary, it also comes with challenges. Effective communication among other strategies has a great impact towards development of PPC globally. Multiple research studies through several evidence based data indicated that adequate knowledge and skill of communication between care providers, patients with serious illnesses and families promoted early pediatric palliative care referral , thus, improving quality of life .

Physicians are urged to apply concept of honesty and openness in the course of discussion with the patient and families about the diagnosis as well as treatment and prognostic without delay. The disclosure of the prognostic includes provision of more information concerning options for cure, upcoming complications during treatment and impact of the illness to the child. A study done by Hawley, (2016) & Doherty and Thabet, (2018) revealed that this was challenging to most physicians which led to reluctance to referral of eligible patients to pediatric palliative care. Other reasons behind the reluctance were pointed out as lack of skills and knowledge about pediatric palliative care, uncertainty of prognosis, assumption that the family might deny the referral, unawareness of palliative care and acceptance by the physicians that the treatment has failed and that they are not competent enough. Even getting to know the right diagnosis, knowing

the right time to refer children and families to PPC was noted to be challenging for physicians. Even though, according to World Health Organization (WHO) palliative care begins at diagnosis through treatment till death and after bereavement. Early and clear diagnosis would help avoid aggressive treatment during pediatric end of life care, hence prolong the life expectancy of a child patient and his/her families

Patients' and families' reluctance as well, delayed pediatric palliative care since they were scared of breaking the bond shared with healthcare providers in case they are to join to a new team of care making pediatric palliative care referral difficult. Different opinions concerning the diagnosis and choice of treatment by physician contributed to the delayed process of PC referral. This impacted the treatment options as well as obstruction in clinical trials by several institutions even though the patients were eligible.

Involving adolescents in decision making about their medical treatment was a way to adhere to the autonomy and respect their dignity. However, age priority limited children to participate in decision-making, hence involving their parents to advocate for them. Other parties would also get involved in the participation of the decision –making with the consent from the child's parents. Their participation made them to open up and share thoughts about their feelings towards treatment and illness. On the contrary, parents, due to fear of causing anxiety and distress to their children, undisclosed some information which was noticed to affect the quality of life and care, hence, delay to provision of PPC services . Parents were emotionally affected during the process of caring for a child at the end of life phase, thus finding it difficult to accept the forthcoming death of a child.

Care providers being culturally competent contributed towards development of pediatric care. Language barrier tend to fragment information between the care providers, children with serious illness and families, especially during disclosure of information about diagnosis and /or during the process of decision making concerning their goals of care. Some cultures due to cultural beliefs and religion felt uncomfortable talking about death as it was believed to bring bad omen which was death. A study by Kaye et al, (2015) suggested that publishing of materials in languages that patients and families from dif-

ferent cultural background understand makes communication easier during the end of life care. On the other hand, suggestion on provision of information through interpreters is possible. .

Misinterpretation and misunderstanding of palliative care to represent death or end of life by children with serious illness and families delayed referral to pediatric palliative care. As a result, physicians proposed to rephrase of the word “palliative care” to “supportive care” which would enable children with serious illnesses and their families to approve on pediatric palliative care referral, thus early provision and access to Pediatric Palliative Care (PPC) services. Early referral to PPC is likely to improve the quality of life by prolonging the life expectancy, thus less aggressive treatment as well as distressful symptoms (Hui and Bruera, 2015 and Hawley, 2017).However, some of the healthcare providers are on denial about implementing pediatric palliative care services placing children with life limiting conditions and their families in a distressful situation, thus lowering the quality of life and care (Friedrich et al, 2018). Nevertheless, healthcare providers have responsibility to explain the meaning of palliative care and what it entails for children living with life limiting illnesses or life threatening illnesses and their families to erase the perception of palliative care to refer to death. Contrary, findings from a study by Hawley, (2017) mentioned that combination of either of the two phrases with additional terms such as “pain and symptom management” was likely to fade the role of palliative care, thus hindering the fulfillment of patients’ needs by the interdisciplinary team.

Basic Palliative Care (PC) training sessions for healthcare providers as well as introduction of PC in medical and nursing school curricula enables students familiarize themselves with PC. Data collected from variety of research studies indicated that health care providers, patients and families were not aware of palliative care, thus, ability to provide the care to patients and families in need of the services were limited. For this reason, formal training and education for all healthcare providers and PC specialist both in developed and developing countries is recommendable to enable them advocate as well as provide optimal quality care for patients with serious illnesses such as cancer and their families. Some of the patients and families had problem in experiencing palliative care due to cultural norms, for example, the Latino children with life –limiting condition that

moved to US (Munoz-Blanco et al, 2017). Other barriers that impeded the experience of pediatric palliative care for the Latino children suffering from serious illness were poverty, traditional social support and healthcare system. For example, poverty hindered the process of death and bereavement and secondly, the cost of healthcare was a burden to families with financial strains. According to the Latino culture, being away from the family and lack of social tradition support brought a feeling of isolation. The period of the training should be adequate enough to enable the care providers gain enough skills and knowledge about pain and symptom management, palliative care and end of life care among others. Additionally, the continuation medical program for oncologists is necessary to attain new skill in the field.

Three levels of training, particularly in Low and Medium Income countries, which were outlined according to recommendations within WHA resolution and Lancet Commission report, consisted of the Palliative Care Approach, General Pediatric Palliative Care (PPC) and Specialist PPC. The palliative care approach focusing on educating undergraduate or pre-registration students and qualified healthcare professionals enabled them integrate PPC in unspecialized settings. General palliative care training was meant for those who participated in provision of PPC, though not as a daily job. The authors had mentioned that several curricula and programs are available for this kind of training, which has been noticed to be important in utilizing myths and barriers to Pediatric Palliative Care (PPC) provision as well as support PPC specialists. Specialist palliative care training was for those specialized in PPC. Programs focused particularly different specialized care providers, for example, doctors, nurses or multi-professionals. The authors further mentioned that education for parents and family members to enable them support and take care of their child was necessary as well as training for community health workers in Low and Medium Income Countries (LMICs) (Downing et al, 2018).

Advocacy at all levels of healthcare systems, for example, community and national levels as well as regional and international palliative organizations would be of beneficial, particularly in low and medium income countries. For example, advocacy at community level, patients and families become aware of Pediatric Palliative Care (PPC) and make use of them when they need it. This entitles them to PPC programs, fade the myths and

beliefs patients and families have about use of opioids as well as home care support (Downing et al, 2018).

Family-centered advanced care planning during End of Life care with the HCPs enabled a child and his/her family make wishes regarding EOL care. Discussion with the family about End of Life (EOL) as well as during bereavement brought comfort to the families and prepared them for the dying process. Care planning and coordination processes consisted of advance care planning, emotional, social & spiritual support, bereavement, care coordination and continuity, symptom control and forms/phone calls after death (Kaye et al, (2015) .Establishment of therapeutic alliance through effective communication among patient, family and interdisciplinary would strengthen the bond and trust, thus, provision of optimal quality care during the EOL care (Blazin et al, 2018).

Sufficient resources, for example, to cover salaries, would enhance the employment of well trained and skilled physicians, nurses, social workers, specialist and other care providers to help meet the needs and goals of children with serious illnesses and their families. From the findings, it was noted that with the rapid growth of children and families in need of Palliative Care (PC) services, there was need for more PC programs. On the contrary, availability of funds was noted not to totally solve the problem since recruitment of the appropriate care providers was going to be a challenge (Doherty and Buera, 2018). This insufficiency overweighs patients and families living in low and medium income countries than those living in high income countries, where resources such as oncological units and interdisciplinary team are adequate. International Children's Palliative Care Network (2015) principles of children palliative care states that children living with life threatening illness have right to palliative care. However, insufficient resources in developing countries affected the quality of life, particularly for children living with chronic illness. The scarcity of palliative care programs as well as access to the services, particularly specialist palliative care program, among the children with chronic illness and families living in community hospitals and rural areas was noted. Though, a study by Neha and Vivek, (2016) stated that the provision of services such as hospices and palliative care units, were highly recognized among children with life threatening illness, such as cancer living in urban areas.

Home-based care was also noted to be a major PC service which could benefit children at the status of End of Life care. Despite being a Palliative Care service offered outside hospital settings, children and families had a possibility to choose a suitable environment comfortable for them during the Pediatric End of Life care. This was contrary to hospital settings, where parents felt they were limited from spending peaceful last moments with their children after death. On the other hand, home-based care enabled the siblings to spend last moments with their loved one. Support could be available from the community or even volunteers and this also applied in the hospital-based settings. A study done by Kaye et al, (2018) revealed that most deaths happened at homes compared to hospitals. This was due to the higher percentage of home care as a choice of care location by many children and families during the terminal care. This was evidenced by the differences in financial strains with lower cost of taking care of a child during EOL care at home rather than hospital.

Evidence based data enabled the recognition for urgency of pediatric palliative care. For example, collecting data of the symptoms children with serious illnesses as well as the rate of pain would advocate for the need of pediatric palliative care services. A study by Downing et al, (2018) suggested that provision of evidence based data outlining how the resources have been used in some countries where provision of PC services was claimed to be a barrier due to limited resources was necessary. With no medication and treatment for children with life limiting conditions or life threatening conditions, provision of palliative care services was impeded in the resource poor countries. First reason being lack of resources while other one cultural beliefs and myths about the analgesics. Children living with HIV were noted to be limited to the antiretroviral therapy treatment while chemotherapy and radiotherapy treatments for children suffering from cancer due to lack of machines. Despite the fact that medications such as morphine were costly, administering them, if they were available, was challenging. This made it difficult to prevent pain and distressful symptom especially during the pediatric end of life care which alleviated the quality of life of children with serious illness and families. The use of opioids among children with serious illnesses and families was a hindrance due to multiple beliefs about addiction, tolerance, respiratory depression among others, which really impacted their quality of life and care (Downing et al, 2018 and Friedrich, et al 2018).

Patient Protection and Affordable Care Act “ Concurrent Care for Children” protects and guarantees children of optimal quality of care by providing concurrent care through Medicaid or the State Children’s Health Insurance Program. This mostly affected children with life threatening illness and families residing in the United States. Even though concurrent care enabled the children with serious illness and families’ access to PPC services, this did not favour children with life expectancy less than 6 months (Kaye et al, 2018). However, these limitations were noted to exempt children and families who needed provision of early PPC services such as Community-based Pediatric Palliative Care. On the contrary, life expectancy of a child living with chronic illness was difficult to predict.

8 CONCLUSIONS

The findings of the study were based on the research question to investigate the development of pediatric palliative care and the challenges that comes with its development globally. The development of pediatric palliative care globally requires several strategies to enable its implementation into the healthcare system. Effective communication is the major factor towards development of palliative care. It promotes collaboration and teamwork among the multidisciplinary team, thus improve children and families quality of life and care. In addition, it helps build a strong relationship between children with serious illness, families and multidisciplinary team making decision-making process concerning treatment choices and goals easier. Excellent communication enabled the multidisciplinary team to provide comfort to patients and families during the end of life care and after bereavement, thus promoting quality of life and care.

Trainings and education for healthcare providers both in developing and developed countries improved the quality of life and care of children with life limiting condition such as cancer and families through alleviating pain and suffering during pediatric end of life care. Through the training, healthcare providers and specialist oncologist were able to prevent pain and distressful symptoms and provide right treatment to patients with serious illness. The training gave them an opportunity to gain knowledge and skills on how to communicate efficiently with children and families during end of life care, manage pain and symptoms, to disclose information about prognosis, prognostic and treatment goals among others, since it was observed to be the greatest challenge in development of pediatric palliative care.

The development of pediatric palliative care comes with challenges which hindered the provision of quality care to children with serious illness and families. Insufficient communication among the multidisciplinary team, patients and families deteriorated the quality of life when inadequate information concerning prognosis and goals of treatment were unmet. Shortage of workforce due to lack of trained healthcare providers, particularly, in resource poor countries hindered the provision of palliative care to all children and families in need of it. Although training of the healthcare providers in the resource

poor countries was a big issue due to lack of funds and decrease of donors in the past years.

The access to affordable medication for all children during pediatric end of life care to relieve pain and symptoms for children and families at the end of life care was necessary, especially in resource poor countries. Possibility of administering medications through different routes such as interdermal, parenteral, rectal among others helped with pain management for children who oral route was challenging, for example neonatal. Early palliative care reduces unnecessary staying at the hospital as well as aggressive treatments, thus prolonged life expectancy. Cultural competency helped healthcare providers improve the quality of life through efficient communication with culturally diverse children and families. Discrimination of children and families from different cultural background/ethnic group /race affects the quality of life and care of children and families who need pediatric palliative care services. Thus, practicing humanistic care for patients and families faced by hardships such as cultural beliefs, religion and socio economic status is necessary to enable the provision of high quality of care.

8.1 Recommendation

There were three recommendations outlined based from the findings of the study. Findings based on development of pediatric palliative stressed on provision of enough period of training for the healthcare professionals caring for children with serious illness. However, there has not been specific ideal period of the duration for palliative care training. Thus, the study recommends enforcement of a standard pediatric palliative care training period for all care providers caring for children with serious illness and families. Secondly, evidence was obtained from the previous studies on need and importance of bereavement support, but no detailed information on how to support the families, particularly, those from different cultural background with different religion and belief. Therefore, the study recommends provision of services that responds with different cultural norms as per religion and beliefs. Third recommendation involves children with chronic condition and their families. The aim of pediatric palliative care is to promote quality of life of children living with chronic condition or life-limiting condition and families. Investigations from previous studies conducted were mostly of children living

with life-limiting condition such as cancer, thus the study recommends research on children with chronic condition.

8.2 Strength and limitations of the study

Though the goals of this study have been accomplished through answering the research questions addressed previously, limitations were observed. . Using verification strategies such methodological coherence, sufficient sampling, developing a dynamic relationship between sampling, data collection and analysis, theoretical thinking theoretical and theory development enables the researcher to modify the research process which builds up reliability and validity, thus ensuring rigor. Being that this study was conducted as a literature review, there was lack of global generalization during the search using key word “Development of pediatric palliative care globally”. Articles including the word “globally” were not recognized within the search, which limited the global perspective of research study. Several articles retrieved including at least one of the key words were not having information relevant to the research question whilst, those which were relevant had limited access. Most articles used for analyzing the study were from the latest studies. Therefore, the researcher was able to use latest information to investigate the research study.

REFERENCES

- Benini, F., Orzalesi, M., Santi, A., Congedi, S., Lazzarin, P., Pellegatta., Zen, L.D., Spizichino, M. & Alleva, E. (2016). 'Barriers to the development of pediatric palliative care in Italy', *Ann Ist Super Sanità*, Vol. 52(4), pp. 558-564.
- Bergsträsser, E. (2013). 'Pediatric palliative care: a reflection on terminology', *Palliative care*, vol.7, pp.31- 36.
- Blazin, L. J., Cecchini, C., Habashy, C., Kaye, E. C. & Baker, J. N. (2018). 'Communicating Effectively in Pediatric Cancer Care: Translating Evidence into Practice', *Children (Basel, Switzerland)*, Vol. 5(3), 40.
- Cheng, B. T., Rost, M., De Clercq, E., Arnold, L., Elger, B.S. & Wangmo, T. (2018). 'Palliative care initiation in pediatric oncology patients: A systematic review', *Cancer medicine*, 8(1), pp. 3-12.
- Connor, S.R. & Bermedo, M.C.S Global Atlas of Palliative Care at the End of Life; Worldwide Palliative Care Alliance: London, UK, 2014.
- Coad, J., Patel, R. & Murray, S. (2014). 'Disclosing Terminal Diagnosis to Children and Their Families: Palliative Professionals' Communication Barriers', Vol. 38(1-5), pp, 302-307
- Crozier, F. & Hancock, L.E. (2012). 'Pediatric Palliative Care: Beyond the end of Life', *Continuing Nursing Education*, Vol. 38(4).
- Delgado, E., Barfield, R.C., Baker, J.N., Hinds, P.S., Yang, J., Nambayan, A., Quantana, Y. & Kan, J.R. (2010). 'Availability of palliative care services for children with cancer in economically diverse regions of the world', *Eur J Cancer*, 46 (12), pp. 2260-2266.

Doherty, M. & Thabet, C. (2018). 'Development and Implementation of a Pediatric Palliative Care Program in a Developing Country', *Frontiers in public health*, Vol.6, 106.

Downing, J., Boucher, S., Daniels, A. & Nkosi, B. (2018). 'Paediatric palliative care in resource-poor countries', *Children (Basel, Switzerland)*, Vol. 5(2), 27.

Duodecim. Palliatiivinen hoito.

Duodecim (2019). Available at: <https://www.duodecim.fi/2018/01/12/hyva-palliatiivinen-hoito-lievittaa-karsimysta-ja-vaalii-elamanlaatua/> Accessed 30 April 2019

Franca, J.R.F.S., Costa, S.F.G., Lopes, M.E.L., Nobrega, M.M.L., Batista, P.S.S. & Oliveira, R.C. (2018). 'Existential experience of children with cancer under palliative care', *Rev Bras Enferm (Internet)*, Vol.71 (3), pp.1320-1327.

Franca, J.R.F.S., Costa, S.F.G., Lopes, M.E.L., Duarte, M.C.S., Morais, G.S.N., Silva, E.C., Zaccara, A.A.L., Oliveira, T.C., Dias, K.C.C.O. & Coutinho, M.F.O. (2016). 'Importance of Palliative Care in Pediatric Oncology', *International Achieve of Medicine*, Vol. 9(35).

Friedrichsdorf, S. J. & Bruera, E. (2018). 'Delivering Pediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliative', *Children (Basel, Switzerland)*, Vol. 5(9), 120.

Graneheim, U. H. & Lundman, B. (2004). 'Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness', *Nurse Education Today (2004)*, Vol. 24(2), pp. 105-112.

Hawley, P. (2017). 'Barriers to Access to Palliative Care', *Palliative care*, Vol. 10

Hui, D. & Bruera, E. (2015). 'Integrating palliative care into the trajectory of cancer care.', *Nature reviews. Clinical oncology*, Vol. 13(3), 159-71.

Paterson and Zderad: Humanistic Theory. Available at:
<https://www.slideshare.net/vaisakhgopakumar/humanistic-nursing-theory-ppt>. Accessed: 10 February 2019.

Kaye, E.C., Rubenstein, J., Levin, D., Baker, J.N., Dabbs, D. & Friebert, S.E. (2015). 'Pediatric Palliative Care in the Community', *A Cancer Journal for Clinicians*, Vol. 65(4), pp. 315-33.

Khraisat, O. M., Alakour, N. A. & O'Neill, T. M. (2017). 'Pediatric End-of-life Care Barriers and Facilitators: Perception of Nursing Professionals in Jordan', *Indian journal of palliative care*, Vol. 23(2), 199-206.

Knapp, C.A. & Contro, N. (2009). 'Family Support Service in Pediatric Palliative Care', *American Journal of Hospice & Palliative Medicine*, 26(6), pp. 476-482.

Lynch, T., Connor, S. & Clark, D. (2013). 'Mapping levels of palliative care development: a global update', *Journal of Pain and Symptom Management*, vol.45 (6), pp.1094-1106.

Muñoz-Blanco, S., Raisanen, J. C., Donohue, P. K. & Boss, R. D. (2017). 'Enhancing Pediatric Palliative Care for Latino Children and Their Families: A Review of the Literature and Recommendations for Research and Practice in the United States', *Children (Basel, Switzerland)*, Vol. 5(1), 2

Neha, C. & Vivek, K. (2016). 'Challenges to Palliative Care in Pediatric Patients', *Journal of Palliative Care & Medicine*, Vol. 6(3).

Paterson and Zderad: Humanistic Nursing. Available from:
<https://humanisticnursing.weebly.com/about-pz.html>. Accessed: 15 March 2019

Population Reference Bureau. 2017. Available at:
http://www.prb.org/pdf17/2017_World_Population.Pdf. Accessed: 5 February 2019

Rodriguez-Galindo, C., Friedricha, P., Morrissey, L. & Frazier, L. (2013). 'Global challenges in pediatric oncology', *Current Opinion*, Vol, 25(1)

Sasaki, H., Bouesseau, M. C., Marston, J. & Mori, R. (2017). 'A scoping review of palliative care for children in low- and middle-income countries', *BMC palliative care*, 16(1), 60.

Weaver, M. S., Heinze, K. E., Bell, C. J., Wiener, L., Garee, A. M., Kelly, K. P., Casey, R.L., Watson, A. & Hinds, P.S. (2015). 'Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review', *Palliative medicine*, Vol. 30(3), 212–223.

Together for short life (2019). Available at: <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care>. Accessed : 6 February 2019

WHO (2019) Definition of Palliative Care. Available at: <https://www.who.int/cancer/palliative/definition/en>. Accessed: 5 February 2019

ICPCN (2015) Available at: <http://www.icpcn.org/principles-of-cpc>. Accessed: 19 February 2019

Levels of CPC provision – ICPCN (2015). Available at: <http://www.icpcn.org/1949-2> Accessed 20 February 2019.

Zietman, A.L. (2013). 'Falsification, Fabrication, and Plagiarism: The Unholy Trinity of Scientific Writing', *International Journal of Radiation Oncology *Biology * Physics* (the Red Journal), Vol. 87(2), pp.225-227.