



**Knowledge, Attitudes and Practice of Pediatrics Palliative Care from the
Viewpoint of Health Workers and Social Workers at Caritas Baby Hospital:
Perspective for new Practice and Policy Implementation.**

THESIS

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By: Wafa' Musleh

Advisor: Dr. Eman Abu-Sa'da

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On 15th of May, 1997 I lost my twin soul in a car accident. My life since that time took another direction as I found myself so close to sick children and their families, trying to help them with all the positive energy and strength gifted me by God. By serving these needy people, I felt myself much closer to late Wisam Musleh, my cousin and twin soul who I truly miss very much in my life.

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Abstract

Pediatric Palliative Care is considered as a new approach in the Palestinian context. It aims at improving the quality of life of patients and their families facing problems as a result of life-threatening illness. This approach deals not only with physical problems but also with psychosocial and spiritual aspects. Palliative Care is introduced to Caritas Baby Hospital in Bethlehem recently in order to improve the health services and the quality of life of chronically ill children and their families. Caritas Baby Hospital is one of the oldest hospice care unit and facility in the Middle East.

The purpose of this research is to investigate the knowledge, attitudes and practice of the health care providers (physicians, nurses, social workers, administration staff, radiologists, physiotherapists, laboratory technicians, dietary service staff as well as pharmacists) at Caritas Baby Hospital regarding pediatric palliative care. In addition to investigate in specific the role of social workers regarding Palliative Care. Based on theory of change, and within the framework of KAP (Knowledge, Attitude, and Practice), a mixed method study has been conducted to examine and assess knowledge, attitude and practice of pediatric palliative care within the facility. A survey that measured KAP was administrated to 155 health providers, and in addition a 2-hour in-depth discussion group was conducted with 4 social workers at the hospital to illuminate the role of social work in Palliative care. Two standardized instruments were used to measure the knowledge and the attitudes; these are FACTOD and PCQN, and another tool for Practice. The researcher used SPSS to analyze principle component analysis, as well as the descriptive analysis of the socio- demographic of the health workers and their knowledge and attitudes towards palliative care.

The main findings of this study showed that despite that the majority of the health professionals are not having a clear idea about the palliative care but understand the need to integrate palliative care into the health system and mostly highlight the need to use it to improve the quality of care

for terminally ill children and their families. On the other hand this research showed that social workers are playing a major role in palliative care. Moreover, respondents showed good general knowledge on PC, but also the respondents seemed to have a moderate attitude towards PC. Regarding pain management, or the relation with patient and their family, respondents seem to have an uncertain or unfavorable attitude. Regarding practice, respondents generally seem to have good ideas of suitable practice of PC, in the meantime they don't seem to understand how PC is to be practiced in details. The recommendations of this study are to provide intensive training in the hospitals to the health professionals that deal with life threatening illness, and establish medical guidelines and protocol in which palliative care is fully integrated. Also the role of social workers was discussed to integrate social work role in a multidisciplinary team to provide Palliative care.

Research Objective and Methodology

Introduction

Caritas Baby Hospital, in Bethlehem, is the only hospital in Palestine uses a holistic medical approach for children. It was initially founded in a small rented house towards the end of 1952. Afterwards, it was developed into a modern children's hospital in 1978, making it one of the earliest pediatric palliative care units within the Middle East, given that no evidence was found through the literature review of earlier facilities. "Children's Relief Bethlehem" is an association independently founded in 1963 in Switzerland; the association was founded in order to financially secure the work in Bethlehem (Caritas Baby Hospital, 2013).

The Importance and the rationale of the research study

Being a social worker for over 15 years at the ICU section of the CBH in Bethlehem, the researcher has been confronted regularly with incurable and chronic illnesses of the children that mostly exhaust their family resources and are considered as a challenge for the whole family to deal with them. The role of the researcher as a social worker at the hospital has been to accompany the physician when informing the family about the chronic illness of their child, or his/her incurable illness, or even the expectance of the death of their child. It has never been easy to confront such situations, yet I have had to stand beside the physician and find the suitable words to inform a family in each situation respectively, as well as to support the family during their stay at the hospital. This repeated situation has raised many questions to the researcher as a social worker, among them was regarding the lack of a private space for the families to allow them to talk privately and express their feelings. The lack of privacy for those families has not been the only issue to consider, the devastating situation that the child and the family go through during this hard time has imposed issues of the services that could

be needed to improve the quality of life for the children and their families during this time. It has become clear that specialized coordinated efforts from the health professionals and the social workers are needed in order to provide support and help the families to find resources to deal and cope with the incurable illness and chronic diseases of their children. These issues have motivated me to need for a qualified and integrated team who is dedicated to provide not only medical care for the children, but also psychological, social and spiritual support for both the children and their families.

Moreover the lack of studies on palliative care in Palestinian medical system makes this research a pioneer in discovering this issue and its importance for those who work in the medical field and for the role of the social workers at the hospitals with the hope that this research would be the ground of introducing a new service and practice at the CBH in Bethlehem. Moreover more research is needed to be done in this issue to be built on this research, especially taking into consideration the families and their needs.

Aims

This study aims at assessing Knowledge, Attitudes, and Practice of health providers providing pediatric palliative care at CARTIS Baby Hospital (CBH). By acquiring data from practitioners involved with CBH, the current status of pediatric palliative care is understood better for future development of this service by CBH. Furthermore, the study aims at assessing the role of social workers in pediatric palliative care for further improvement, whilst addressing the unmet needs of patients and their families.

Research questions of this thesis are composed of three parts:

1. What do health providers at CBH offer as palliative care? Can they offer more services?
What are the competences of the social workers or other specialists to meet the need of patients and their families?

2. What are the knowledge, attitudes and practices of the CARITAS Health Providers towards palliative care?
3. What is the association between knowledge among professionals towards palliative care and selected demographic variables?

Objective

The general objective of the study is to improve the quality of health care at CARTIS by initially creating a baseline of knowledge, attitude, and practices of pediatric palliative care among health providers and social workers to be able to implement positive change onto service delivery in pediatric palliative care. This in turn, helps to improve the current situation by providing targeted methods to change knowledge, attitude, and practices of pediatric palliative care within the hospital.

Research questions

1. What are the knowledge, attitudes, and practices of the CARITAS health providers towards palliative care?
2. What is the correlation between knowledge on palliative care, and the selected demographic information? Are years of experience and age having any effect on knowledge on pediatric palliative care? Or has it only been very recently introduced?
3. What role do social workers play within pediatric palliative care? How can social workers integrate themselves better into the pediatric palliative care team?

Operationalization of research concepts

Key Words: “Palliative Care, Pediatric Palliative Care, Health Providers, Knowledge, Attitudes, Practice, Theory of Change, Pediatric Health Care and Quality of Life”

- **Palliative Care:** Palliative care is defined by the World Health Organization (WHO, 2016) 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.

- **Pediatric Palliative Care:** According to (WHO), the following principles represent adult palliative care:
 - *"Provides relief from pain and other distressing symptoms;*
 - *Affirms life and regards dying as a normal process;*
 - *Intends neither to hasten or postpone death;*
 - *Integrates the psychological and spiritual aspects of patient care;*
 - *Offers a support system to help patients live as actively as possible until death; cvc their own bereavement;*
 - *Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;*
 - *Will enhance quality of life, and may also positively influence the course of illness"* (WHO, 2016)

- **Health Providers:** physicians, nurses, social workers, administration staff, radiology, physiotherapist, laboratory technicians, dietary service staff and pharmacists, as defined in the organization settings at CBH.

- **Knowledge in KAP:** is the understanding, familiarity, and awareness, regarding a certain topic. This includes Knowledge measurement in the study which is important before starting the procedure of forming awareness, due to the significance of evaluating the environment in which the change will occur within. (Ross, M. M., McDonald, B., & McGunness, J. (1996). The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursmg*, V23, 126-137).

- **Attitude in KAP:** is the settled way of thinking, feeling or common belief, towards a certain topic. Counting Attitude in the KAP survey vary according to the literacy,

residence, economic principles, level of education and the degree to which the issue under study would be publicized in media and elsewhere. (Frommelt, K. H. (n.d.). Frommelt Attitudes Toward Care of the Dying Scale (FATCOD). Retrieved from University of Buffalo).

- **Practice in KAP:** is the way respondents demonstrate their knowledge, beliefs and attitudes through their actions. Including Practice in KAP is important to create a baseline for the study, as eventually the change could be detected through the baseline of the respondents' practices and the results of the cohort study (Ross, M. M., McDonald, B., & McGunness, J. (1996).
- **Theory of Change:** is the connection between the program/intervention methods, and KAP or improvement of knowledge, attitude, and practice (Lindgren, 2015).
- **Quality of life:** In pediatric patient populations, where children range in their cognitive and verbal skills and parents are often proxy-reporters and decision-makers for their children, it becomes even more challenging to assess the child's perception of what he/she considers to be quality of life. Pediatric Quality of Life (QoL) has been defined by others as a multidimensional construct that is a state of complete physical, mental, and social well-being for a child; however, these definitions of QoL that are referring to the physical, psychological, and social domains of health, are seen as distinct areas that are influenced by a person's beliefs, expectations, and perceptions of health (Evan E, Calonico E, Tan B, and Zeltzer L, 2012).
- **Pediatric Health Care:** is a model of medical care that promotes holistic care of children and their families where each patient/family has an ongoing relationship with a healthcare professional (National Association of Pediatric Nurse Practitioners, 2017).

Methodology

The study used mixed research methods to assess the knowledge, practice and attitudes of CARITAS health providers toward Palliative Care. The qualitative collection methods included in-depth discussion group with social workers.

The quantitative collection methods included a survey answered by all the health providers at CBH given that the survey is designed specifically to the aims of this study and the respondents.

Research Design

Based on the literature review, research questions, and objectives of the study, different types of quantitative and qualitative tools for the various target groups are designed:

Quantitative Method

- ✓ Based on cross-sectional study a questionnaire was adopted for the health providers and social workers.

Qualitative Method

- ✓ In-depth discussion group for social workers.

Piloting

Given the fact that this stage is essential in any survey to avoid possible shortcomings of the survey instrument, the researcher is aware of the sensitive nature of this stage and its importance in measuring the effectiveness and the credibility of the survey methodology and questionnaire. On the tactical level, the pilot study is an instrumental in identifying all items that may adversely affect the validity of our instruments (due to linguistic and /or conceptual ambiguity). Following the finalization of the questionnaire drafts, a small survey was conducted using a sample of 10 health providers. This was important to test the understanding of the questionnaires by the target audience as well as the validity of some of the questions.

Instrument design

- ✓ Construct Reliability using Cornbrash-Alpha stability coefficient (α)

The construct reliability was measured by the determination of the internal arrangement of the standard paragraphs that reached the rate of (0.842) according to Cornbrash-Alpha, which is a good rate. This rate is an evidence for the survey's reliability and its instrument.

Reliability Statistics	
Cornbrash's Alpha	N of Items
.842	24

- ✓ Content Validity and reliability of the survey to adapt it to Palestinian content:

As we presented earlier the three measurements for this study that were intended to measure knowledge, attitudes and practices were conducted in different contexts and in different countries and it was checked for its reliability and validity. The question that was raised how to apply this instrument in the Palestinian settings and specifically to Caritas Baby Hospital and to assure that the instruments are clear, appropriate and meaningful for the health professionals of CBH. In order to adapt the instrument to the targeted population of the study the researcher conducted two focus groups to the health care providers working at Caritas Baby Hospital in Bethlehem including: Physicians, Nurses, Social workers, administration staff, Radiologists, physiotherapist, laboratory technicians, dietary service staff and pharmacists. The aim of these groups was to check the degree that the instruments are clear in meaning and purpose, and whether the constructs that are used are related and obvious to the respondents. Each focus group consisted of fifteen members of various professions.

The first meeting started the discussion about the concept of Pediatric Palliative care, the importance of integrate it into the system of Caritas Baby Hospital. All participants

assured that this is a new practice as a “Concept” though it is practiced during work among patients and their families, and they agreed of the importance of integrating it into the system of the institution. At the end of the discussion, I shared with participants the survey that I adopted from FACTOD “Frommelt Attitudes toward Care of the Dying Scale” and the PCQN “Palliative Care Quiz for Nurses”, which was translated to Arabic language since it is the participants mother language. This survey assessed the knowledge, attitudes and practices of the Health care providers, The recommendation of all participants at that meeting was to distribute the survey in English, because by translating it they said that the meaning of a lot of the constructs were not clear.

Another recommendation, which was raised and agreed upon among all participants, is kinds of medications that were mentioned in the survey aren’t available in Palestine, so the pharmacist helped to find the replacement of these medications available in Palestine.

After including all the recommendations that were raised during the first group discussion, the group was invited again to another meeting. In this second time, the survey was administrated to the participants in its original English language with all the suggested recommendations that was taken into consideration from the first group discussion. This session assured the face validity of the survey, the clarity of the concepts and the constructs and it showed that the survey is addressing the issues for the study that are meaningful, obvious and make sense for the health professionals and social workers.

During the administration of the survey for the whole population, the administration of Caritas Baby Hospital was cooperative and they organized three days for the employees to fill the survey and gave staff one hour paid leave to fill it. By that, CBH helped the researcher to get a high response rate.

Data collection

- ✓ Field work team

Data collection was done using face to face interviews. The researcher, as well as two field workers conducted the interviews.

- ✓ Training of the Field Researchers

One day training was conducted. The training included a comprehensive explanation of the aims and objectives of the study. As the trainees went over the questionnaire, an explanation of the different terminologies and indicators used were discussed.

The researcher presented the criteria for quality and accuracy control that abides in such survey studies, as well as logistical, administrative and financial issues related to field work. The importance of not jeopardizing the quality of data collection in any way was expressed.

The need for continuous communication and coordination with the area researcher for proper feedback was discussed and emphasized to solve any possible obstacles, and find solutions in case any field work was halted.

Sampling and sample selection

- ✓ Target population

The study population consisted of all health providers at Caritas Baby Hospital (CBH).

The total population is 163 health providers.

- ✓ Sample frame

The sample population frame consisted of all local health providers at Caritas Baby Hospital (CBH). This consisted of identified variables of the health providers as well as classifications that were used to produce strata. The classification variables were: gender, job title and department.

- ✓ Sample design:

The study targeted all health providers at CBH as shown in the table

Department	Sample Size		
	Female	Male	
Dietary Services	7		7
I.C.U.	7	5	12
Laboratory	6	6	12
Medical	3	14	17
Mothers' Residency	10		10
Neonatal Ward	7		7
Out Patient Clinic	9	7	16
Pediatric Wards	54	9	63
Pharmacy	2	1	3
Physiotherapy	5	1	6
Radiology		5	5
Sisters	1		1
Social Services	4		4
Grand Total	115	48	163

Quality of Data during the data collection process

To ensure data quality, the following steps were followed in the field during the data collection process

- ✓ Random visits by the field researchers for the data collectors during the field work.
- ✓ Review, monitor and adjust all questionnaires filled by the data collectors on a daily basis.

Data Entry

Data entry was done using Access 2013 database. The same image of the questionnaire was recreated using the Access database. All control and logical rules was defined to prevent data entry errors. The control rules defined in the database minimize data entry errors. For example, one of the questions took only two values 1 or 2, hence the database didn't allow any other values

to be entered for this variable. More logical checks were imposed on the data entry process to ensure logical consistency among logically inter-related variables. A special program was used in the data entry process featuring the following characteristics:

- Possibility of working in an Arabic language version on the computer screen
- Limiting data entry errors to the minimal
- Ease of presenting data for the various sections of the questionnaire
- Ability of checking the rational sequence in the questionnaire data

Moreover, 10% of the questionnaires were double entered to make sure that the quality of the data entry is up to the standards.

Data Cleaning

Data cleaning is very important to the efficiency of data. Data cleaning is the process of ensuring that a set of data is correct and accurate. During this process, records were checked for accuracy and consistency, and they were either corrected or deleted as necessary. After all questionnaires were entered, SPSS was used to produce initial frequency tables to the variables and examined to try to detect any data errors or outliers using univariate and multivariate techniques. A cross-validation of results through conducting various cross-tabulation was also done.

Data Analysis

The statistical software (SPSS) was used for data analysis which included:

- 1) Frequency tables.
- 2) Cross-tabulations of the main variables in the study. The analysis included tabulating the data by type of gender, education, job title, years of experience, and age in complete years.

3) Principal component analysis - Factor Analysis was used to compute the knowledge index, attitude index. After that, the below operational definition was applied:

1. Favorable attitude = ≥ 50 of the total score of (FATCOD) Scale.
2. Unfavorable attitude = $< 50\%$ of the total score of (FATCOD) Scale.
3. Good knowledge = $\geq 75\%$ of total score of the Palliative Care Quiz for Nursing (PCQN) scale
4. Poor knowledge = $< 75\%$ of total score of the PCQN scale
5. Knowledge aspect of practice = the Health provider must have a knowledge on PC regarding application of practice.
6. Good knowledge aspect of practice = $\geq 75\%$ of total knowledge aspect of practice questions.
7. Poor knowledge aspect of practice = $< 75\%$ of total knowledge aspect of practice questions.

Data Transformation

The items in the index of this dissertation were recorded for the sake of clarity and ease of analyses, which also explains the cut off used 0.5 and 0.75; Strongly agree (coded as 5) and agree (coded as 4) were recorded to “Agree to some extent” as 3, on the other hand, Strongly disagree (coded as 1) and disagree (coded as 2) were recoded to “Disagree to some extent” as 1. Finally, uncertain was recoded from 3 to 2.

Literature Review

Introduction

Palliative care as a service was introduced early in 1976 by St Christopher's Hospice in the care of people with neurological disease with an aim of improving quality of life of patients and their families. Since then, it has seen global development where palliative care is recommended for different types of terminal diseases, it has its own regulations, and standardizations, and it can be found worldwide in different forms. World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness". (WHO, 2016) It does so by accommodating to the patients physical, mental, and spiritual health. Generally speaking, patients with chronic diseases, such as cancer and cardiovascular diseases are in most need of palliative care, but it is also used for "kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis." (WHO, 2015).

Nevertheless, some of the main diseases in adults in need of palliative care range from cardiovascular diseases (38%), cancer (34%), and chronic respiratory disease (10.3%) (WHO, 2016). Furthermore, data provided by WHO show that around 40 million people worldwide are in-need of palliative care, whereas only 14% are receiving it (WHO, 2015).

Evidence of the start of palliative care was seen at the start of 1900 through a few hospice facilities, but its development did not significantly start until St. Christopher's Hospice was built in England, in 1967, by Cicely Saunders. Today, there is much legislation and foundations for palliative care around the world, their aim are to research and provide palliative care for as many in-need patients as possible. As for the Middle East, palliative care was only introduced to the Arab countries in the early 1990's, and is only applied on a large scale in a few countries. In Palestine, specifically, palliative care is not a widely used concept, and has only been introduced

briefly in 2008 through Al-Sabeel Society. (Shawawra & Khleif, 2011). Furthermore, studies on pediatric palliative care are very rare within the region, and its practice is very limited to specific countries.

Definition of terms

Pediatric Palliative Care is essentially Palliative Care but more focused on Children, and their specific needs. Palliative care, also known as hospice care, differs from normal medical care by including mental, spiritual, and personal health. “Palliative care is a philosophy and structured system for delivering care that improves the quality of life of patients and their families facing problems associated with life threatening illnesses—through prevention and relief of suffering by means of early identification, assessment and treatment of pain and other physical symptoms and problems: physical, psychosocial, and spiritual.” (CSI & University of Minnesota, 2016).

According to WHO, the following principles represent adult palliative care:

- *“Provides relief from pain and other distressing symptoms;*
- *Affirms life and regards dying as a normal process;*
- *Intends neither to hasten or postpone death;*
- *Integrates the psychological and spiritual aspects of patient care;*
- *Offers a support system to help patients live as actively as possible until death;*
- *Offers a support system to help the family cope during the patient’s illness and in their own bereavement;*
- *Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;*
- *Will enhance quality of life, and may also positively influence the course of illness”*
(WHO, 2016)

Palliative care for Children doesn’t differ much from adult care; it is based under these principles:

- *“Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.*
- *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 palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*

- *It can be provided in tertiary care facilities, in community health centers and even in children's homes.” (WHO, 2016)*

International Work on Palliative Care

As Palliative Care was developed, different organizations and associations emerged concentrating on providing support facilities for caregivers, and also assessing palliative care, its effects, feasibility, approaches, and so on. For example, in Europe, the European Association of Palliative Care represents over 50,000 healthcare professionals and volunteer caregivers in 40 countries (COMECE, 2016). The association has helped in the implementation of palliative care as an essential service in the EU. By 2008, every member in the EU had palliative care service (COMECE, 2016).

Nevertheless, there are different palliative care systems applied around the world, where not all of them are covered through legislation, or implemented through an organization. In Kerala, India, a neighborhood network in palliative care (NNPC) was formed. It is a community program where local volunteers are trained “to identify problems of the chronically ill, and intervene effectively, with an active support from a network of trained professionals” (WPCA, 2014). Within 10 years, NNPC became a network of 500 community owned programs for palliative care in India, with more than 15,000 volunteers across. The high success rate for this program is mainly due to fact that it is community based, but also, the support of local and state government has helped in the financial support of this program. A similar community-based model was found in Florida, US, Hope Hospice. Although the network reached by Hope Hospice was smaller than India’s community based network, it has helped by providing palliative care for a section of people whom are not eligible for palliative care benefits from the government (WPCA, 2014).

Hospice Casa Sprinted, a charity founded in Romania in 1992, is also one of the successful models for palliative care. It did not only help in introducing palliative care to Romania, but also majorly contributed in teaching palliative care, and designating university courses for it.

It is now regarded as a resource center in all of Eastern Europe, “providing theoretical and clinical palliative courses for countries in the Balkan region” (WPCA, 2014). In China, Ho Chi Minh City Cancer Hospital is one of the largest cancer centers in the world, with approximately 1,700 in-house patients daily (WPCA, 2014). It has adopted palliative care, and over years of training and development, established a ward, and other facilities dedicated for palliative care. Given that most of their cancer patients die at home, they are trying to further develop their care program by adding palliative care at home, but it is very costly.

Many other models exist worldwide, from government based models, to community programs. The biggest problem facing palliative care and palliative home care are the expenses needed. Nevertheless, some organizations are charity based, and are aiming to provide this financial care. But given the model in India, community based palliative care had a very high rate of success and reach, which resulted in the financial aid from the government to further develop and expand (Prem, et al., 2012). The development of this model and application in different countries would cater for many terminally ill patients, and provide home-care for them.

Knowledge, Education, & Attitudes on Palliative Care Internationally

International comparative KAP (knowledge, attitude and practice) studies on palliative care are hard to find for different reasons starting with the different formulations of different studies in different countries, where the questionnaires and their assessments are different, or concentrating on different specialties, or not mentioning the specialty consistently within certain studies. Nevertheless, a European collaborative study was conducted for physicians across 7 countries, Belgium, Denmark, Italy, Netherlands, Sweden, Switzerland, and Australia as well. (Miccinesi, et al., 2005). Physicians from different specialties that were seen to be involved in end-of-life care were asked to participate; these specialties were “Anesthesiology general practice, geriatric, gynecology, internal medicine, neurology, nursing

home medicine (only in the Netherlands), oncology (not a registered separate specialty in the Netherlands), pulmonology and surgery.” 10139 questionnaires were answered and studied, giving most countries a 60% response rate, Italy 39%, Australia 50%, and Belgium 58% (Miccinesi, et al., 2005). At least 50% of physician respondents in all countries considered themselves religious, and between 7-22% to have a specific life philosophy. Whist religious participants had more support for the statement that good palliative care prevents requests of physician-assistant death (Miccinesi, et al., 2005). Non-religious participants were less supportive of this statement. Female physician and older physicians were also more supportive of the statement that good palliative care prevents the request of physician-assisted dying. Training in palliative care was also associated to the perspective of the participants of non-treatment methods, where physicians with training were more supportive of palliative care. Last but not least, physicians who have attended to more terminally-ill patients were also more supportive of palliative care than physicians who deal with less terminal diseases (Miccinesi, et al., 2005).

Knowledge, Attitude, and Practice on Pediatric Palliative Care Internationally

Pediatric palliative care does not differ much from adult palliative care, the main difference is that children are still growing, and this needs to be taken into consideration, medically, mentally, and spiritually. This might result in a different approach towards children, for example in considering medical treatments, or psychological effects. Furthermore, decisions are made through the parents, or guardians, with either no-involvement, or minimal involvement of the children, and this has its own effect itself on either the child's needs, or diagnosis and understanding symptoms. Pediatric palliative care can thus help the decision making mechanism of the parents, with a more medical, or a therapeutic perspective (Anon., 2016).

Two cross-sectional design surveys on pediatric palliative care were done in the USA aiming to assess the situation palliative care and pediatric palliative care. The first was given to all the

nurses at the Children's Hospital in Philadelphia in 2005, and second was in the state of Florida, in 2011, where the survey was given to all the nurses in Florida registered at CMSN. In Philadelphia, a 44% response rate was found, gaining answered questionnaires from 410 nurses working within the pediatric sector (Feudtner, et al., 2013). Respondents were in moderate agreement on their comfortably working with terminally-ill children, but neutral in difficulty of talking about death and dying. The main conclusion of this study was that nurses with longer experience working within the pediatric care sector, disregarding specialties, were more comfortable working with terminally-ill children, less difficulty talking about death and dying, "and a greater depth of competency in the provision of pediatric palliative care" (Feudtner, et al., 2013). In Florida, 279 nurses successfully answered the survey, obtaining a 61% success rate (Knapp, et al., 2011). The cross-sectional survey was formatted using 11 statements about palliative care and pediatric palliative care, 4 positive statements, and 7 negative statements. 64.1% of nurses had more than 20 years of experience, and 59.4% of them were older than 50 years old (Knapp, et al., 2011). The results of the study show that in regards to the positive statements 39% - 90% were in agreement of them, depending on the statement, where 90% of respondents were in agreement to the statement that "Hospice services should be discussed with patients prior to the terminal stage of their disease" (Knapp, et al., 2011). As for the negative statements, 5%-40% were in agreement of the negative statements, where the 5% was in agreement of "I do not think it is appropriate to approach families whose children have a life-limiting illness and are in the mid-stage of illness to talk about palliative care" (Knapp, et al., 2011). Within this study, it was seen that only one multivariable was of enough significance in determining attitudes on pediatric palliative care, which was also the amount of years of experience.

Knapp and Thompson also performed a cross sectional survey published in 2011, but started in 2008, titled "Factors Associated with Perceived Barriers to Pediatric Palliative Care: A Survey of

Pediatricians in Florida and California”. The states were chosen for two main reasons, firstly they had pediatric palliative care initiatives, and secondly both are big states which are diverse in population. A total of 303 pediatricians responded to the survey, giving it a response rate of 44.4% (Knapp & Thompson, 2011). The study had two main aims, “(1) to describe the barriers to pediatric palliative care as reported by a group of pediatricians practicing in two large States in the US; and (2) to identify factors associated with these perceived barriers.” (Knapp & Thompson, 2011). Results showed two main barriers perceived by pediatricians, firstly, 95% of respondents thought that reluctance of family member to pediatric palliative care is a main barrier, and the second barrier is the family’s view of pediatric palliative care as giving up on their child which had 94% agreement from pediatricians (Knapp & Thompson, 2011). Six significant factors affecting the perceived barriers were found, which are, gender, age, years of practice, number of medicated patients, practice setting, and race/ethnicity. Of most consistency, gender, practice setting, and number of medicated patients was most prominent.

Another study conducted on pediatrics was given to member of the Section of Critical Care at the American Academy of Pediatrics. The self-administered questionnaire had 102 respondents from North America, with a response rate of 14% (Jones & Carter, 2010). The study “Pediatric Palliative Care: Feedback from the Pediatric Intensivist Community” conducted its ‘questionnaire based on 4 main categories 1) Clinical experience, 2) Educational experience, 3) Barriers and Resources, 4) Opinions on palliative care services.

Results showed that for the category of clinical experience, most respondents were “confident” in performing clinical procedure on children. As for the educational experience, respondents found that “informal methods, such as experiential learning in direct patient care, trial and error, self-guided learning and learning from a role model” (Jones & Carter, 2010) was most efficient. Among the barriers and resources, the biggest barrier found was lack of communication, and lack of hospice or pediatric palliative care units/specialized physicians as a resource. Last but not

least, opinions on palliative care services showed that the most helpful were services that dealt with transition between hospitalization and the community; with the least ranked one was the assistance in the withdrawal of life-continuing treatments.

“Underlying barriers to referral to pediatric palliative care services: Knowledge and attitudes of health care professionals in a pediatric tertiary care center in the United Kingdom” is another study on pediatric palliative care, conducted to increase access of patients to palliative care. The questionnaire used covered 4 categories, 1) Demographic background, 2) Clinical and palliative experience, 3) Knowledge and attitude on palliative care and its services, 4) Confidence in skills related to palliative care provision and referral (Twamley, et al., 2013). The survey was distributed at a large pediatric tertiary care center in the UK, a total of 132 respondents answered the survey, obtaining a 14% response rate. Doctors and nurses from different specialties were the major respondents, but also pharmacists, psychologists and therapists from different specialties and units (Twamley, et al., 2013). 74% of respondents had 7 years or more of experience, and have worked with the hospitals palliative care specialty team (Twamley, et al., 2013). The main results of the study showed that knowledge on palliative care and its benefits was high between the respondents, with a positive attitude towards it. Nevertheless, referrals to palliative care was less than it should have been given knowledge and attitude, this was found to be due to the association of palliative care to end-of-life or dying, this association has thus become one of the main barriers of pediatric palliative care referrals (Twamley, et al., 2013). Within the conclusion of this study, a recommendation for further research on family reluctance and association of doctors or caregivers of death and palliative care referrals was recommended. This is because although this study found the previous association with lack of referrals, one of the more discussed barriers within research is family reluctance as a significant barrier to referrals.

A literature review conducted in 2012 to outline “Cultural and Religious Considerations in Pediatric Palliative Care”. Using 37 published articles of relevance to this context, dating

between 1995-2011, 7 themes emerged that have an effect on pediatric palliative care (Wiener, et al., 2012):

1. *(The role of culture in decision making: The family structure within a culture has an effect because the decisive family members can include more than just the immediate family, or that the head of family is the one to make the decision (whether immediate or extended).*
2. *Faith and Involvement of Clergy: People with different religions or faiths may have different perspectives or preferences on the involvement of pastoral caregivers in pediatric palliative care. Furthermore, certain religions or faiths may have their own rituals for care, or end-of-life situations.*
3. *Communication, Spoken and Unspoken: Different spoken languages between patient and the medical team would result in miscommunication between both ends. Even unspoken communication can result in misunderstanding of gestures depending on the background of the receiver.*
4. *Communication with Children about Death, Truth Telling: Parents are not always supportive of disclosure of the diagnosis with the child. This has to do with either their emotional state, or the inability to accept their child's faith, or for cultural reasons, where it is more acceptable to not tell the child his/her diagnosis. "Lack of communication can lead to emotional distance at a time when closeness is most needed" (Wiener, et al., 2012).*
5. *Meaning of Pain and Suffering: Miscommunication between patient, parents, and doctor could result in less effective pain management. Where parents might exaggerate their child's suffering in certain aspects, or the child is not willing or capable of communicating with the doctor on his own. Furthermore, culturally, pain is perceived differently, where in some cultures it is seen as an experience to help go to heaven, or in other cultures, people do not disagree with physicians, and would not ask for better pain management.*
6. *Meaning of Illness, Dying, & Death: Different cultures perceive suffering and illness differently, for example, in some cultures illness is seen as a result of an imbalance of energies. Understanding the child's perspective and spiritual state would help in optimizing end-of-life palliative care.*
7. *Location of End-of-Life Care: Depending on cultures and beliefs, there could be a preference of where death occurs, at home or at the hospital or care unit. Other cultures may not care about location of death, but comfortability and spiritual state of death).*

Palliative Care in the Middle East

Palliative care in the Middle East was not known until it was introduced in Saudi Arabia in 1992 (Zeinah, et al., 2012). Although this was over 20 years ago, its progress within the region did not reach all countries. Within the gulf area, Saudi Arabia is the leading country in palliative care, although it is concentrated in hospitals only. Nevertheless, Oman, UAE, Qatar, and Bahrein have all established palliative care systems within the past two decades, but palliative care was still in hospitals mainly, with a few clinics established in certain countries or cities. (Zeinah, et al., 2012).

Al-Sham area in the Middle East, consisting of Iraq, Jordan, Palestine, Lebanon and Syria has had slower progression within the Palliative care sector, Jordan taking the lead in its development.

Palliative care was introduced to Jordan in 1993, through the formation of AlMalath Foundation for Humanistic Care, which offered palliative care in conjunction with two main hospitals in Jordan. Al-Malath also built a hospice with a team of volunteer nurses to provide mental, physical and spiritual care for patients. Jordan Palliative Care Initiative (JPCI) was formed in 2001, and agreed with the ministry of health to incorporate Palliative care into the health system. Although the regulations are yet to be applied properly, a team of palliative care workers were hired at King Hussein Cancer Center (KHCC) to provide hospital support and home care, making KHCC one of the most comprehensive centers for palliative care in the Middle East. On the other hand, Iraq does not have any palliative care systems, and there are no records of the situation in Syria. (Zeinah, et al., 2012).

In Lebanon, a KAP study conducted in 2005, gave out self-administrated questionnaires to a selection of nurses and physicians in 15 hospitals around Lebanon, with specialties of medical, surgical, pediatric, acute critical care, oncology, and obstetrics/gynecology, to determine knowledge, attitude, and practice of palliative care. The final amount of questionnaires analyzed were 868, giving it a 23% response rate (Huijer, et al., 2009). The results found that the main factor effecting knowledge, attitude, and practices were the specialties of physicians and nurses. Although none of the physicians or nurses had continuous education in palliative care, the majority of them were able to identify the goals, assumptions, and components of palliative care, physicians scoring higher than nurses. (Huijer, et al., 2009). The study also found that 24.4% of oncology nurses think that palliative care is destructive to hope, and can lead into depression or despair in families and patients.

Nurses and physicians with medical and surgical specialties had a negative view of patients and their family's questions, outbursts, and concerns, nurses more than physicians (Huijer, et al., 2009). On the other hand, most pediatric and acute critical care nurses and physicians, found patient's outbursts, questions, and concerns acceptable under different circumstances. The

negative attitude of certain specialties can be attributed to lack of knowledge and education on palliative care, where the effects and results are not understood properly, it also has to do with the ability of these nurses and physicians of dealing with emotional or terminally ill patients and their families (Huijer, et al., 2009). Although the majority of respondents believe that the patients should know about their diagnosis, there is a discrepancy in its application. In conclusion, although education and knowledge is low for palliative care, and general attitude of nurses and physicians is pro-palliative care, nevertheless, lack of practice within the field sets palliative care back in Lebanon.

Regarding Israel, it probably has the oldest palliative care program in the Middle East, starting in the early 1980's, where oncology nurses within the community were tasked to care for cancer patients at their homes (Ami & Yaffe, 2015). Progress in Israel's palliative care was due to 4 main reasons:

1. Increase of public awareness resulted in an increase for the demand of palliative care. (Ami & Yaffe, 2015)
2. The Dying Patient Legislation. (Ami & Yaffe, 2015)
3. Specialization of nurses in Palliative care; in 2009 the ministry of health took interest in nurses specializing in palliative care, they gained their knowledge or specialty from working in palliative care at hospice centers, hospitals, or home care units. Specialized nurses were then tasked to train and teach the upcoming generation of nurses in palliative care. University level courses were also established for the development of this field. (Ami & Yaffe, 2015)
4. In 2005, the ministry of health applied a new regulation to provide a palliative care unit in every health care center/facility within the next 4 years. The palliative care team at these facilities should include a physician, a nurse, a psychologist, and a social worker. (Ami & Yaffe, 2015)

A study conducted in Egypt at Menofia University Hospital titled “Impact of Palliative Care Education on Nurses’: Knowledge, Attitude and Experience Regarding Care of Chronically Ill Children” was set as a KAP study, using a quasi-experimental design, at the pediatric unit and ICU at the hospital. The aim of the study was to firstly evaluate nurses need and experience regarding palliative care, secondly the development of an education guideline for these nurses, and lastly, evaluation of the impact of the guidelines on the nurses’ education and experience regarding palliative care (S.El-Nagar & Lawend, 2013). A sample of 30 nurses was taken, 63.3% of them had a bachelor in nursing, and 10% were associate nurses. In regards to knowledge, around 50% of respondents answered correctly in regards to pain alleviation methods before the brochure was given, and 76.7% after. As for the reduction of pain threshold due to anxiety or fatigue, 43.3% answered correctly before, and 63.3% answered correctly after (S.El-Nagar & Lawend, 2013). As for the nurses’ attitude on palliative care, the mean and standard deviation were calculated for the answerers before and after, where all values were attributed a p value with high significant difference. The overall attitude towards palliative care increased, where the involvement of the family is more important, or that a dying person should receive honest answers about their conditions. Nevertheless, an increase of mean values was also observed for statements in regards to difficulty dealing with terminally-ill patients, and withholding decision making of the patient (S.El-Nagar & Lawend, 2013). Last but not least, nurses’ practice of palliative care has shown a large increase, where around 6.7% of nurse’s administrated prescribed drug before, but it jumped to 76.7% of nurses administrating drugs. Regarding nurses present when the patient has died, previously only 20% of them have, whilst 60% of nurses were with the patient at death after (S.El-Nagar & Lawend, 2013). In conclusion, there was significant difference in knowledge of pediatric nurses within the facility, this also lead to a high significant change in the attitude and practice of nurses when dealing with terminally ill children.

Knowledge and attitude of nurses in regards to palliative care was also studied in Southeast Iran. A “True, False, & I don’t know” questionnaire was handed to 140 nurses working in hospitals under Kerman University of Medical Science supervision. The response rate was 89%, 116 full questionnaires were used and analyzed. The survey was done to study the nurse’s attitude and knowledge on palliative care; it was focused on three main categories. 1)

Philosophy and principles of palliative care, 2) Management of pain and symptoms, 3) Psychological and spiritual care (Razban, et al., 2015). The majority of respondents were females, 93.8%, 78.5% had no training or education in palliative care, the average years of experience is 8.7 years, and all respondents were Muslim, who do religious activity regularly (Razban, et al., 2015). Results showed that respondents had “moderately negative to neutral attitude towards palliative care, with a total mean score of 2.99 out of 5” (Razban, et al., 2015). Nurses with a more positive attitude on palliative care were either nurses with higher levels of education, or nurses who have personally dealt with a family death. 46.07% of nurses answered correctly for the category “pain management and symptoms” which was the highest score, whilst the category with the lowest score of 19.3% was for the category

“Psychological and spiritual care” (Razban, et al., 2015). The negative attitude of nurses was mainly attributed to the following reasons, firstly, nurses in Iran mainly follow the physician, and can neither medicate nor effect decision making, thus diminishing incentive to learn about palliative care. The nursing shortage and underpayment in Iran would affect their learning incentives as well. Cultural beliefs about death and dying might be a cause of the negative attitude. (Razban, et al., 2015).

Palliative Care in Palestine

In Palestine, palliative care was not part of the health care system, and was only first introduced in Palestine through Al-Sadeel Society in 2008 (Shawawra & Khleif, 2011). Although

Palestinians, as part of their culture, care for the elderly and keep them in-house, the supplement report “Palliative Care Situation in Palestinian Authority”,2011, concluded that there is no evidence of palliative care for cancer patients in and outside of hospitals, nor is there community awareness or a national standard for palliative care (WPCA, 2014).

“Palliative Care and Nursing in Palestine, 2015”, also shows the lack of palliative care in Palestine. Al-Sadeel Society, founded by a nurse and a social worker, as a nongovernmental organization is the only official organization that is providing palliative care and training in Palestine. Its aim is to provide home based palliative care in Palestine, and maintain or increase the quality of life for terminally ill cancer patients (WPCA, 2014). Al-Sadeel society has provided care in 2014 for 544 patients, and 476 family caregivers (Khleif & Dweib, 2015), although 84.7% of the patients were cared for in hospital, 3% at home, and 12.3% at the society’s palliative care clinic (Khleif & Dweib, 2015).

“The Nurses’ Knowledge and Attitudes towards the Palliative Care”, 2015, is a published article in the Journal of Education and Practice, and referenced in “Palliative Care and Nursing in Palestine”. The study was done to assess knowledge and attitude on palliative care among nurses working in hospitals in northern region of Palestine (Ayed, et al., 2015). It covered nurses in 4 main hospitals within the area, and interviewed a sample of 96 nurses using a questionnaire written to assess knowledge, attitude and demographics. Generally speaking, the results show that there is a high percentage of nurses interested in learning about palliative care, 20% of the nurses interviewed have good knowledge on palliative care. Knowledge on palliative care is quite limited though, which is why Khleif & Dweib emphasize on the importance of education on palliative care, and its involvement in our daily lives. They state that palliative care initiative should be developed focusing on “professional training, public awareness, and integrating palliative care into the healthcare system and health education” (Khleif & Dweib, 2015). The

initiative should not only concentrate on nurses, but spread over different professions, from doctors, oncologists, social workers, therapist...etc.

According to the article “Palliative Care and Nursing in Palestine”, a study in the Middle East showed that around 86% of respondents are interested in learning about palliative care, but “The Nurses’ Knowledge and attitude towards the palliative care”, shows that around 20% of nurses have a good level of knowledge on the subject. As for the attitudes, 56.2% of nurses interviewed showed a moderate attitude towards palliative care (Ayed, et al., 2015).

Nevertheless, Khleif & Dweib mentioned that nurses are usually very reluctant or “terrified” of working within the cancer unit, or with cancer patients, this shows that even though they “Like” the idea palliative care, they are more terrified of dealing with terminally ill patients. Physicians and oncologists also require training and education in palliative care. Increase in education on palliative care, and availability of information should be the main priority within this field. An initiative of Al-Sadeel, with the collaboration of the ministry of health is trying to integrate palliative care into the undergraduate nursing course at universities, “So far about 120 graduates had training in palliative care” (Khleif & Dweib, 2015). Physicians and oncologists should be also pushed towards palliative care, by having training conferences, for example, or even including it as a mandatory form of care for cancer patients (as a start), and other terminally ill patients. For this, Al-Sadeel has organized 2 workshops in the past 2 years for health professionals and nurses on palliative care. It is also trying to implement an online course for palliative care in order to spread information, and increase knowledge on the Subject.

Within the Middle East, palliative care is focused on cancer patients alone, and so is most of the research about it. Although it is valid, given that cancer is either the 1st or 2nd cause of death, depending on the country (Zeinah, et al., 2012) (Shawawra & Khleif, 2011). Palliative care for cancer patients is regarded as most important due to its discovery in late stages of its development, thus being terminal within the next period, and no chance of a cure. On the other

hand, palliative care in Israel is provided for different terminal illnesses and for adults and children as well. Palliative care concentration on cancer patients within the Arab countries in the Middle East is probably to increase early detection. Furthermore, one of the main issues for palliative care for these countries is pain management, where doctors and nurses are reluctant to offer high dosage of sedatives or pain killers to patients, and nurses that are applying palliative care cannot amend the dosage. Nevertheless, to conclude the study, palliative care should become available for different types of terminal illnesses in order to try to increase the Quality of Life in these areas, and cover a wider range of people and patients in need of such service.

Pediatric palliative care, on the other hand, is literally almost non-existent in most countries in the region. “In Cyprus, Palestine (West Bank), Iraq, Egypt, Turkey, and Pakistan only few children receive palliative care either in the hospital or at home.” (Knapp, et al., 2012). Due to lack of information, knowledge, or experience, pediatric physicians do not apply palliative care, given that they do not recognize the benefits of its application in the pediatric section, for both the child, and the parent. Not to mention the lack of financial support. KHCC in Jordan established a pediatric palliative care service in 2005, it has “full-time pediatric oncologist, a full-time pediatrician, a pediatric hematology/oncology fellow, and two full-time clinical nurse specialists” (Knapp, et al., 2012). Pediatric palliative care should become a priority for palliative care advancement within the region, for example, in Turkey, Palestine, Egypt & Jordan, children make up one third of the total population, and providing palliative care to children will definitely increase the quality of life for the entire country. According to Pediatric Palliative Care: Global Perspective, the main two reasons for lack of pediatric palliative care in the Middle East, is 1) Lack of funding or regulations by the ministry of health. 2) Low mortality rate, and small number of patients. Furthermore, the main 3 barriers for pediatric care within the region are:

1. Family: The lack of family education or presence of child negligence affects the willingness of families to request palliative care. (Knapp, et al., 2012).

2. Health Care Providers: Lack of awareness or training for care providers limit the availability of palliative care and referrals towards it. (Knapp, et al., 2012).
3. Environment: Palliative care is barely provided in general within the region, let alone in the pediatric section. This constructs a physical barrier for palliative care. (Knapp, et al., 2012).

Pediatric Palliative Care & Social Work

“Social workers play a leading role in the delivery of specialist palliative care....they also play a leading role in the development of academic underpinnings” (Small, 2001). Social work is very similar to palliative care regarding the type of care they provide. Both of these sectors require workers whom provide care outside of the work scope for the person they are looking after “Even though social workers are trained to provide psychological support to individuals facing crisis, loss, and significant transition, they report substantial gaps in their education in end-of-life care(Clark,2004; Kramer et al., 2003” (Jones, 2005) A social worker can acts as a respondent to the emotional and physical effects of acceptance of death, and loss itself (Small, 2001). According to Smalls, 2001, social work and palliative care have similarities as follows:

- “Social work has always been concerned with responding to loss;
- It brings a whole system view, putting individual experience into a wide context;
- Social work has a concern with helping ameliorate the practical impact of change-for example in relation to fiancé” (Small, 2001, pp. 962-963).

In 2005, B.L Jones conducted a study regarding current practice methods of social workers providing end-of life treatment in the pediatric oncology department, and to also identify their best practice or ideal role within the sector. The questionnaire was sent to all members of the Association of Pediatric Oncology Social Workers (APOSW), and a total of 131 respondents, with a 50% response rate. The results of the study showed that social workers most frequently provided “supportive counselling for the family, assessment of the family support structure, help

with financial arrangements; concrete financial resources, and advocate for families' needs, choices, and desires.” (Jones, 2005). As for the ideal roles seen by social workers for them, the roles with the highest 3 ranks were, “counsellor/companion/guide, Advocate/communicator/coordinator of services, & resource broker” (Jones, 2005).

Respondents of this study were asked to rate their importance and preparation for items regarding important practices within the ideal role of pediatric oncology social worker, for importance, the highest ranking was listening to concerns, fears, hopes; supportive counselling for parents; individual psychosocial assessment for the family's' needs. As for preparation rating, respondents were least prepared when tasks involved pain/symptom management and medical discussions. As for rating the most helpful education source, the three top ranks were on the job learning, workshops, and graduate education.

In conclusion, social workers and palliative careers have very similar job description, where the social worker can cover multiple palliative care roles such as psychologist, advisor, family consoler...etc. And as seen through the preferred roles of social workers, they feel more comfortable within these situations, and consider them an ideal role. One thing that should be improved according to Jones,2015, is the medical background of social workers, this is for multiple reasons, firstly it will help the social worker explain the medical situation, results, and treatments to the patient and their families, secondly, social workers can explain/offer alternative treatment methods which might be more viable for the family, and thirdly, a social worker would be able to discuss the patient situation in depth with the medical staff, and finally, with the increased medical involvement of the social worker, they will be more prepared for pain/symptom management of the patient.

Social Workers and CARTIS Baby Hospital

Pediatric Palliative care is to be assessed at CARTIS Baby Hospital (CBH) mainly through a KAP study to understand the degree of knowledge about it, the attitude of staff towards it, and

degree of practice of pediatric palliative care. Although social workers do not usually work in the medical field, their job and ideology as social workers coincides with palliative careers in different ways. Social workers have experience working with difficult cases, providing support, mentally, emotionally, and sometimes physically they generally aim to improve the quality of life. Similarly, palliative caregivers provide emotional, physical, and mental support to their patients and their families, they attempt to ease the process of treatment, or death acceptance, and manage a communication channel between the patient, their family, and the medical team. Given the previously mentioned similarities, it can be said that social workers and palliative caregivers have the same job requirements but in different fields.

Regarding CBH, if improvements were to be done regarding palliative care, social workers involvement is to be considered very beneficial. Social workers already work to improve the quality of life of others, and they already have the basic training regarding the mechanisms used, as they are the same for social workers and palliative careers. Training social workers to become palliative caregivers can be very efficient and useful, where they would mostly learn the medical part of palliative care, but can then become more involved with palliative care, by becoming a member of the palliative care team at CBH.

The addition of social workers as palliative caregivers will improve the quality of pediatric palliative care at CBH greatly. Social workers within the region already have an understanding of the situations; they are initially trained to deal with the family as a whole, taking into account the social background, and the circumstances it is in. Social workers already have the skills to communicate with the different types of people, thus they can close the gap of communication between patients, their families, and the medical team.

KAP & Theory of Change

Knowledge, Attitude and Practice (KAP) Studies

USAID in collaboration with SPRING described KAP survey as a “Quantitative method (predefined questions formatted in standardized questionnaires) that provide access to quantitative and qualitative information” (SPRING & USAID, 2011). They also stated that KAP studies can:

- “Measure the extent of a known situation
- Enhance the knowledge, attitude, and practices of specific themes
- Establish a baseline for use in future assessments and help measure the effectiveness of health education.
- Suggest strategies that reflect specific local circumstances and the cultural factors that influence them” (SPRING & USAID, 2011).

As the name implies, KAP studies focus on three dimensions, Knowledge, Attitude and Practice. Mauri Yambo investigated “KAP as a Model of Behavior Change and Innovative Practice {CSO 589}”, when describing Knowledge, he stated “To know is to be able to do, tell, describe, explain, show or say”. Attitude “refers to an individual’s characteristic way of responding to an object or situation. It is based on experience (or knowledge) and leads to certain behavior or the expression of certain opinions. (Graham and Bennett, 1988:294)” (Yambo, 2016). As for Practise, Yambo refers to it as applied skills, techniques, methods or standard operating procedures (SOP). He argues that practice is applied attitude, and concludes that “Knowledge (changes/modifies) Attitude (Which changes/modifies) Practice.”

KAP Survey Technical Approach

There is increasing recognition within the international aid community that improving the health of poor people across the world depends upon adequate understanding of the sociocultural and economic aspects of the context in which public health programs are implemented. Such information has typically been gathered through various types of cross-sectional surveys, the

most popular and widely used being the knowledge, attitude, and practice (KAP) survey, also called the knowledge, attitude, behavior and practice (KABP) survey (Green 2001, Hausmann-Muela et al. 2003, Manderson and Aaby 1992, Nichter 2008:6-7).

KAP survey (Knowledge, Attitude and Behavior) is a descriptive study of a specific population, to gather data on what is known, believed and done regarding a particular topic. KAP surveys are vital for the creation of behavioral and social change, as its outcomes are the evidence needed for any decision-making process, planning, Implementation and Evaluation. KAP surveys are focused evaluations that measure changes in human knowledge, attitudes and practices in response to a specific intervention. The KAP survey was first used in the fields of family planning and population studies in the 1950s. KAP studies bring to light the social, cultural and economic factors that may influence health and the implementation of public health initiatives.

KAP surveys Collect data through an organized, custom designed questionnaire, which usually tackles specific topics, but could include questions on different General practices and beliefs related to the main topic. Questions could target more than one set of respondents, such as; different categories for example (Doctors and Patients) in health-related questionnaires, in which will be modified upon the targeted information.

KAP surveys can recognize and identify cultural behaviors, factors influencing cultural behaviors, reasons behind their beliefs and people's awareness, providing a clear view on knowledge gaps and needs. In which, sheds light on problems, barriers on program supply and, provides a clear evaluation, throughout baseline, cohort and end line studies, that eventually lead us to solutions for enhancing quality, accessibility of services, estimation of resources that are needed for different activities, as well as measurement of change.

Knowledge in KAP is the understanding, familiarity, and awareness, regarding a certain topic. Including knowledge measurement in the study is important before starting the procedure of forming awareness, due to the significance of evaluating the environment in which the change

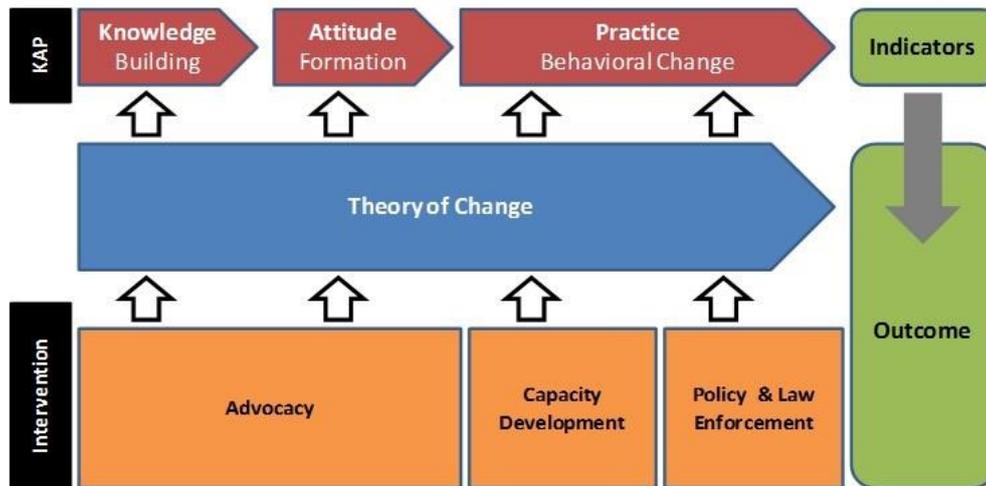
will occur in. Attitude in KAP is the settled way of thinking, feeling or common belief, towards a certain topic. Counting Attitude in the KAP survey vary according to the literacy, residence, economic principles, level of education and the degree to which the issue under study would be publicized in media and elsewhere.

Practice in KAP is the way respondents demonstrate their knowledge, beliefs and attitudes through their actions. Including Practice in KAP is important to create a baseline for the study, as eventually the change could be detected through the baseline of the respondents' practices and the results of the cohort study.

The comprehension of the stages of Knowledge, Attitude and Practice will allow a more practical route of awareness formation, as it will enable the program to be modified more appropriately to the necessities of the community.

Theory of Change

KAP surveys, measuring Knowledge, Attitude, Behavior, and Practice on a certain topic, obtains results by providing an initial baseline for the current situation, which results into target specific recommendations. A KAP study can be done reassess the situation after a change, or implementation of recommendations were done, this is to measure improvement, and acknowledge successful methods of change. "The mediating factor between the program and the KAP measures is the theory of change ... The KAP should focus on the theory of change, not the activities of the program per se. " (Lindgren, 2015). KAP and intervention, and their relation to theory of change (ToC) can be seen in the diagram below;



1 (Lindgren, 2015)

The figure above demonstrates the relation between KAP, Intervention, and Theory of Change. As mentioned earlier, ToC is the connection between the program/intervention methods, and KAP or improvement of knowledge, attitude, and practice. Indicators of KAP show the outcome of the initial intervention. Theory of change is based on the concept that when a new input is added, you will have new output. This can be seen in examples from the literature review, for example, using the study done at Menofia University Hospital in Egypt, Palliative Care was first assessed regarding Knowledge, Attitude, and Practice, results showed that nurses were not very knowledgeable on palliative care, and their attitudes and practice reflected the lack of knowledge as well. A KAP study was done once more after handing out a brochure on palliative care with basic information, this is considered Advocacy, and there was an apparent improvement in knowledge, attitude and practice of palliative care within this unit. This example connects all three, Advocacy, as an intervention method, improved KAP, through ToC. The second KAP study results and indicators showed the positive outcomes of the study.

Theory of Change & CARTIS Baby Hospital

Theory of change is to be implemented in the study regarding pediatric palliative care at CBH. ToC will be the connection between intervention for improvement of pediatric palliative care and improvement of knowledge, attitude, and practice of pediatric palliative care. The proposed set of action, regarding introducing health providers and social workers into pediatric palliative care, is to be firstly done by assessing and creating a baseline for the current KAP of pediatric palliative care at CBH. The results of the baseline study will show target areas for improvement, with a focus on the current and future (improved) role of social workers within palliative care. ToC comes into play after intervention methods are set and accomplished, where a second KAP study should present and show the effects of ToC on the work done. According to ToC, the second study should show how much improvement in Knowledge, Attitude, and Practice of Pediatric Palliative Care at CBH, especially on social workers, given that they are the main focus group of this study. Although intervention will be with social workers, general KAP improvements should be seen through patients, their families, and the medical team, taking into consideration that the social worker will be in contact with all three parties, and second-hand learning usually takes place within such situations.

KAP Survey Methodologies

There are three main types of Methodologies for KAP Surveys:

- 1) **Open Ended Questions:** Open ended questions require respondents to answer freely using their own words. It allows hearing insights on the topic in hand, from a personal perspective, also giving the change for a deeper understanding of problems and their reasons.
- 2) **Partially Categorized Questions:** Partially categorized questions are similar to open ended questions, the difference is, the answers are pre-categorized, and the option “Other” is usually available. Although this type of questions can result in a pre-categorization in a respondent’s mind, which it may result in loss of information, but it also specifies the topic/theme of the results, which increases data accuracy.
- 3) **Closed Questions:** Closed questions include a set of possible answers only. There are 5 main categories for closed question: Multiple Choice; Liker Scale; Numerical; Ordinal; Categorical (Unite for Sight, 2015).

“The basic elements of a KAP survey included:

- **Domain identification:** The domain is the Subject of the KAP study.
- **Identification of the target audience**
- **Determination of sampling methods:** KAP sampling methods usually use a survey or questionnaire administered through interviews.
- **Analysis and reporting:** The data collected through KAP surveys will try to reflect the situation regarding the subject using the least amount of data, but most descriptive. For large sample sizes, computer software such as SPSS or Excel is recommended to organize and analyze the data.” (Unite for Sight, 2015)
- **Principal component analysis (PCA)** will be used to compute the knowledge and attitude indices. PCA is statistical tool used to identify similarities, differences and

patterns in data. PCA would be used on results of FACTOD and PCQN to try to identify factors that have the most effect on palliative care, its knowledge, attitude, and practice.

FACTOD

Frommelt Attitudes toward Care of the Dying Scale

FACTOD is a 30-item tool using Likert Scale, measuring the participants' attitude towards providing care for dying patients. FACTOD is usually used to assess nurses and their attitude and feelings towards situations they work in with their patients, and their families. 2/3 of the questions within the FACTOD measuring scale involve the nurse and the patients only, whereas the last third of questions is regarding the nurse and the patients' families

FACTOD has had its reliability proven in 1988, and again 1998, and so it has been used for different types of research, worldwide, as a measure to assess the nurses' attitude on care of dying.

PCQN

Palliative Care Quiz for Nurses

PCQN was developed to form a tool to test nurses' knowledge on palliative care. It's a 20-item tool, with True, False, and "I don't know" answers. It was developed to assess the nurses knowledge, as well as identify any misconception on palliative care, and lastly to stimulate discussion regarding palliative care.

Literature Review Summary

Palliative care is a way of improving quality of life of patients who are terminally-ill, and their families, through physical, mental, and spiritual health. Internationally, palliative care is studied

more, and in some countries, became mandatory as part of the health care system. Studies have shown that palliative care exists all over the world in different models, but each has its own limitations. Knowledge, attitude, and practice studies had some common results, first, positive attitudes toward palliative care was seen in more experienced physicians, and nurses. At the same time, religious beliefs were also found to have an effect on attitude, as Miccinesi explained in his study, more spiritual or religious physicians are positive towards palliative care. As for knowledge and attitude on pediatric palliative care internationally, similar to the previous results, nurses and physicians with more experience have a positive attitude towards palliative care, but still the common barrier between studies, is the confrontation and communication of palliative care to parents and children, and the association of palliative care or hospice centers with death and dying.

In the Middle East, palliative care has only been formally introduced on a large scale since two decades in Saudi Arabia, and now most of the Gulf countries. Within the regions surrounding Palestine, Jordan has the most advanced palliative care unit at KHCC. Lebanon and Iran have investigated palliative care, and have found lack of knowledge, has resulted in the negative attitude towards palliative care. This was seen in the results of the study at Menofia Hospital in Egypt, where quasi study showed improvement in knowledge, attitude, and practice of nurses. Palestine on the other hand, has only been formally introduced to palliative care in 2008, where Al-Sadeel society now run clinics for palliative care, and have designated teams for it.

Common barriers found for pediatric palliative care are lack of communication, and truth in telling the children about their condition and diagnosis. Other results found that perceived reluctance of parents, and negative overview of palliative care with death, is another barrier for palliative care.

Limitations of the study:

Some of the limitations of this research study are as follows:

1. This study was conducted only to all health care providers that are working at Caritas Baby Hospital amounting to 163 employees and consisted of Physicians, Nurses, Social workers, administration staff, Radiologists, physiotherapist, laboratory technicians, dietary service staff and pharmacists. That means the researcher used Caritas Baby Hospital as a case study, so it can't be generalized to other Palestinian hospitals because we need much more in-depth studies to all the hospitals in Palestine, using the theory of change within the framework of KAP study.
2. Palliative care is a new concept that not all the health providers are aware of; they are practicing it without really knowing a basic knowledge of it, so we have to work to raise the awareness about this concept, by conducting workshops, and lectures at the universities. This study should be replicated after introducing the concepts in order to see the amount of change in attitudes and knowledge regarding palliative care.
3. The number of the social workers that participated in the focus group that was done at Caritas Baby Hospital is very small; only four social workers who are the only social workers at the Hospital. This small number would prohibit us from generalizing the results of the data regarding the role of the social work in Palliative Care. The issue of Palliative care is a new concept that the social workers need to address when working in medical setting, even though the social workers at Caritas Baby Hospital have some understanding and awareness of the concept, but meaning of the implementation of the such intervention at the hospital level and even at the outreach program has not been fully explored and discussed at the different levels (family, community and society) of the roles of the social workers. And that is why it is worth to address the issue with more social workers who work at the medical field.

Data analysis

Socio-Demographics of Health Workers

The study was done for all health providers/workers at Caritas Baby Hospital, gaining a total of 155 respondents. (66%) of respondents were females, and (33%) were male, having a mean age of 38.52 ± 10.73 SD (with a range from 22 – 64). The majority of respondents were nurses (61%), (14%) were physicians, (6%) laboratory technicians, (6%) administration staff, (4%) social workers, (4%) physiotherapists, (3%) radiologists, (3%) dietary service staff, and (1%) pharmacists.

Table 1 Socio-Demographic of Health Workers at CBS

	<i>Frequency</i>	<i>Percentage</i>
	155	100%
<i>Age</i>		
< 30	43	27.7%
30 - 39	34	21.9%
40 - 49	46	29.7%
50 +	32	20.6%
<i>Level of Education</i>		
Diploma	52	33.5%
Bachelor	74	47.7%
Master degree and more	29	18.7%
<i>Working Experience</i>		
1 – 4	43	27.7%
5 – 9	30	19.4%
10 – 14	21	13.5%
15 +	61	39.4%

Health Workers Knowledge Towards PC

Ninety percent of respondents knew the definition of PC, but only (34%) agreed that PC is appropriate when a patient is in deteriorating conditions. (93%) of respondents agree that the extent of the disease determines the method of pain treatment, (95%) agree that adjuvant therapies are important in pain managements, but also (75%) agree that drug addiction is a major problem when morphine is used in long term pain management. (49%) of respondents agree that

during terminal stages drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea, and (87%) agree that the use of placebos is appropriate as a treatment of some types of pain. (92%) of respondents agreed that the manifestations of chronic pain is different than acute pain, and (72%) agree that Opioids are an effective analgesic for the control of chronic pain. (54%) of respondents agree that the philosophy of PC is compatible with aggressive treatment, and (61%) agree that PC requires emotional detachment, also (83%) agree that the accumulation of losses renders burnout inevitable for those working in PC. Lastly, (85%) of respondents agreed that terminally ill patients have the right to choose DNR, but also (86%) agree that terminally ill patients should be encouraged to have hope against all odds.

Table 2 Distribution of Health Workers Knowledge on PC at CBH

<i>Characteristic</i>	<i>Yes N (%)</i>	<i>No N (%)</i>
<i>Do you know the definition palliative care?</i>	140 (90%)	15 (10%)
<i>Palliative care is only appropriate in situations of a downhill trajectory or deterioration in conditions.</i>	52 (34%)	102 (66%)
<i>The extent of the disease determines the method of pain treatment.</i>	141 (93%)	11 (7%)
<i>Adjuvant therapies are important in managing pain.</i>	142 (95%)	7 (5%)
<i>Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain</i>	117 (75%)	38 (25%)
<i>The provisions of palliative care require emotional detachment.</i>	94 (61%)	60 (39%)
<i>During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea.</i>	74 (49%)	78 (51%)
<i>The philosophy of palliative care is compatible with that of aggressive treatment.</i>	83 (54%)	70 (46%)
<i>The use of placebos is appropriate in the treatment of some types of pain.</i>	132 (87%)	20 (13%)
<i>Opioid (Morphine) is not an effective analgesic for the control of chronic pain.</i>	43 (28%)	111 (72%)
<i>The accumulation of losses renders burnout Inevitable for those who work in palliative care.</i>	125 (83%)	25 (17%)
<i>Manifestations of chronic pain are different from those of acute pain.</i>	141 (92%)	13 (8%)
<i>Terminally ill patients have the right to choose "Do not resuscitate" (DNR).</i>	130 (85%)	23 (15%)
<i>Terminally ill patients should be encouraged to have hope against all odds.</i>	133 (86%)	21 (14%)

Distribution of Health Workers Attitude According to Degree of Agreement Towards Items of FACTOD

Out of all health workers respondents, (1/3) & (3/7) strongly disagree and disagree, respectively, that PC should be only given to dying patients. Almost (1/2) of the respondents strongly disagree that they should withdraw their involvement with the patient as they are near death. (1/9) & (4/9) of respondents strongly agree and agree, respectively, that family members who stay close to the dying person often interfere with a professional's job regarding the patient. (2/5) respondents agree that the length of time giving PC to a dying patient will frustrate them, (2/7) respondents disagree to the previous, and (1/5) are uncertain. More than a third of respondents (35.9%) disagree that it is difficult to form a close relationship with the family of the dying patient, almost a third (28.8%) are uncertain of the previous, and less than a third (27.5%) agree to it. Also (37.7%) of respondents disagree with the phrase that they are afraid of becoming friends with chronically ill or dying patients, but (20.5%) are uncertain and (20.5) agree with the previous statement. Half of the respondents (50%) agree that addiction to pain medication should not be a nursing concern when dealing with dying patients, (21.4%) disagree with that statement. As for the statement that death is not the worst thing that can happen to a person, a total of (44.1%) strongly agree and agree to the statement, but also a total of (42.8%) disagree and strongly disagree to the same statement. Table (3) below shows the full results for respondent's attitude towards items of FACTOD

Table 3 Distribution of Health Workers Attitude According to their Degree of Agreement Toward Items of FACTOD

	SA (%)	A (%)	U (%)	D (%)	SD (%)
<i>Palliative care is given only for dying patient</i>	6 (3.9%)	20 (12.9%)	14 (9.0%)	67 (43.2%)	48 (31.0%)
<i>As a patient nears death; the health providers should withdraw from his/her involvement with the patient.</i>	2 (1.3%)	15 (9.9%)	13 (8.6%)	48 (31.6%)	74 (48.7%)
<i>Giving palliative care to the chronically sick patient is a worthwhile learning experience</i>	51 (32.9%)	82 (52.9%)	13 (8.4%)	8 (5.2%)	1 (0.6%)
<i>It is beneficial for the chronically sick person to verbalize his/her feelings</i>	86 (55.8%)	57 (37.0%)	4 (2.6%)	3 (1.9%)	4 (2.6%)
<i>Family members who stay close to a dying person often interfere with a professionals' job with the patient.</i>	16 (10.3%)	70 (45.2%)	33 (21.3%)	32 (20.6%)	4 (2.6%)
<i>The length of time required to give palliative care to a dying person would frustrate me</i>	6 (3.9%)	63 (40.9%)	31 (20.1%)	45 (29.2%)	9 (5.8%)
<i>Families should be concerned about helping their dying member make the best of his/her remaining life</i>	69 (44.8%)	79 (51.3%)	3 (1.9%)	1 (0.6%)	2 (1.3%)
<i>Family should maintain as normal an environment as possible for their dying member.</i>	64 (41.3%)	82 (52.9%)	6 (3.9%)	1 (0.6%)	2 (1.3%)
<i>The health providers should not be the one to talk about death with the dying person</i>	47 (30.3%)	49 (31.6%)	24 (15.5%)	24 (15.5%)	11 (7.1%)
<i>The family should be involved in the physical care of the dying person.</i>	47 (30.5%)	93 (60.4%)	8 (5.2%)	5 (3.2%)	1 (0.6%)
<i>It is difficult to form a close relationship with the family of a dying member.</i>	7 (4.6%)	42 (27.5%)	44 (28.8%)	55 (35.9%)	5 (3.3%)
<i>There are times when death is welcomed by the dying person</i>	11 (7.2%)	73 (47.7%)	36 (23.5%)	19 (12.4%)	14 (9.2%)
<i>Palliative care for the patient's family should continue throughout the period of grief and bereavement.</i>	37 (23.9%)	90 (58.1%)	16 (10.3%)	11 (7.1%)	1 (0.6%)
<i>The dying person and his/her family should be the in-charge decision makers</i>	42 (27.1%)	87 (56.1%)	17 (11.0%)	8 (5.2%)	1 (0.6%)
<i>Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.</i>	21 (13.6%)	77 (50.0%)	16 (10.4%)	33 (21.4%)	7 (4.5%)
<i>Palliative care should extend to the family of the dying person.</i>	40 (25.8%)	90 (58.1%)	10 (6.5%)	14 (9.0%)	1 (0.6%)
<i>When a patient asks, "health provider, am I dying?" I think it is best to change the Subject to something cheerful.</i>	18 (11.7%)	66 (42.9%)	20 (13.0%)	38 (24.7%)	12 (7.8%)
<i>I am afraid to become friends with chronically sick and dying patients.</i>	14 (9.3%)	31 (20.5%)	31 (20.5%)	57 (37.7%)	18 (11.9%)
<i>I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.</i>	22 (14.6%)	76 (50.3%)	20 (13.2%)	23 (15.2%)	10 (6.6%)
<i>I would be uncomfortable talking about impending death with the dying Person.</i>	38 (24.8%)	70 (45.8%)	20 (13.1%)	18 (11.8%)	7 (4.6%)
<i>It is possible for health providers to help patients prepare for death.</i>	16 (10.3%)	85 (54.8%)	17 (11.0%)	29 (18.7%)	8 (5.2%)
<i>Death is not the worst thing that can happen to a person.</i>	22 (14.5%)	45 (29.6%)	20 (13.2%)	33 (21.7%)	32 (21.1%)
<i>I would feel like running away when the person actually died.</i>	14 (9.2%)	55 (36.2%)	18 (11.8%)	51 (33.6%)	14 (9.2%)
<i>I would not want to be assigned to care for a dying person</i>	15 (10.2%)	41 (27.9%)	24 (16.3%)	53 (36.1%)	14 (9.5%)
SA: Strongly Agree, A: Agree, U: Uncertain, D: Disagree, SD: Strongly Disagree					

Knowledge Aspect of Practice of Health Workers Towards PC

When assessing practice PC by respondents, (69%) of respondents agreed that they initiated PC discussion during diagnosis, (23%) when the disease progresses, and (8%) at the end of life (the rest of the questions are multiple response questions). As for informing terminally ill patients about their diagnosis, (46%) answered yes and (49%) depending on the family wishes. The factor considered the most when dealing with terminally ill patients is the psychological factor (78%), and when addressing it, (87%) agreed that they do so with emotional support, and only (10%) do so by hiding the truth. (92%) of respondents said that they involve the patient in the decision making process, and (68%) agreed to involving the family as well. (78%) of respondents assess patients' pain by grade of face, and intensity. The table below (Table (4)) shows the full results for this section.

		Yes n (%)	No n (%)
Initiate palliative care discussion	During diagnosis	107 (69%)	48 (31%)
	When the disease progress	99 (63.9%)	56 (36.1%)
	At the end of life	83 (53.5%)	72 (46.5%)
Do you inform terminally ill patients about their diagnosis?	Yes	71 (45.8%)	84 (54.2%)
	No	24 (15.5%)	131 (84.5%)
	Depending on families wish	75 (48.4%)	80 (51.6%)
	Inapplicable	8 (5.2%)	147 (94.8%)
Factors considered when dealing with terminally ill patients	Spiritual	114 (73.5%)	41 (26.5%)
	Medical situation	108 (69.7%)	47 (30.3%)
	Cultural	106 (68.4%)	49 (31.6%)
	Psychological	119 (76.8%)	36 (23.2%)
Cultural assessment during patient care should include	Truth telling and decision making	109 (70.3%)	46 (29.7%)
	Preference regarding disclosure of information	40 (25.8%)	115 (74.2%)
	Dietary preference	15 (9.7%)	140 (90.3%)
	Language, family communication	93 (60%)	62 (40%)
	Perspective on death, suffering & grieving	65 (41.9%)	90 (58.1%)
Addressing psychological:	Emotional support	134 (86.5%)	21 (13.5%)
	Counselling the patient	94 (60.6%)	61 (39.4%)
	Hiding the truth	16 (10.3%)	139 (89.7%)
Whom do you involve in decision making?	Patient	136 (87.7%)	19 (12.3%)
	Family	100 (64.5%)	55 (35.5%)
	My own	19 (12.3%)	136 (87.7%)
	The health professionals	29 (18.7%)	126 (81.3%)

Communication to the family of terminally ill patient depends on?	Family’s ability to assimilate	121 (78.1%)	34 (21.9%)
	Their involvement in decision making	113 (72.9%)	42 (27.1%)
	Your willingness to disclose information	58 (37.4%)	97 (62.6%)
How do you assess patient pain?	Location	95 (61.3%)	60 (38.7%)
	Grade with face	120 (77.4%)	35 (22.6%)
	Intensity	119 (76.8%)	36 (23.2%)
	Quality	88 (56.8%)	67 (43.2%)
Degree of spirituality	Very spiritual	54 (34.8%)	101 (65.2%)
	Spiritual to some extent	95 (61.3%)	60 (38.7%)
	Not spiritual	5 (3.2%)	150 (96.8%)

Factor Analysis & Data Weighing

“Factor analysis is a method for explaining the structure of data by explaining the correlations between variables. Factor analysis summarizes data into a few dimensions by condensing a large number of variables into a smaller set of latent variables or factors. It is commonly used in the social sciences, market research, and other industries that use large data sets.” (Minitab, 2017)

Computing “Knowledge” Indicator

Knowledge was calculated as an indicator through factor analysis and weighing, in order to compare it to the socio-demographic data obtained. Firstly, questions regarding knowledge, A1 to A14, were put through an SPSS function “Factor Analysis”, in order to measure each component and its significance to knowledge. The test used KMO and Bartlett’s correlation matrix, and Varimax method. The results are on a scale from -1 to 1, where the high correlations have higher numbers (disregarding the sign), and sign represents whether it is negative or positive significance. The following table represents these results, the items were:

Table 4 Values of correlation of Knowledge Variables obtained through Factor Analysis

a4 Adjuvant therapies are important in managing pain.	.661
a6 The provisions of palliative care require emotional detachment.	.568
a14 Terminally ill patients should be encouraged to have hope against all odds.	.560
a13 Terminally ill patients have the right to choose “Do not resuscitate” (DNR).	.551

a9 The use of placebos is appropriate in the treatment of some types of pain.	.393
a7 During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	.150
a8 The philosophy of palliative care is compatible with that of aggressive treatment.	.145
a1 Do you know the definition palliative care?	.113
a10 Opioid (Morphine) is not an effective analgesic for the control of chronic pain.	.101
a12 Manifestations of chronic pain are different from those of acute pain.	.062
a11 The accumulation of losses renders burnout Inevitable for those who work in palliative care.	-.022
a3 The extent of the disease determines the method of pain treatment.	-.058
a2 Palliative care is only appropriate in situations of a downhill trajectory or deterioration in conditions.	-.093
a5 Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	-.121

The top 5 values, shaded in light red, are of the highest correlation (highest number disregarding signs), and the 5 cells shaded in light blue have the lowest correlation to knowledge, as the numbers show, disregarding the sign. As for positive and negative significance, most factors have positive effects, except for the bottom four variables (A5, A2, A3, & A11) with negative signs, representing a negative significance.

The absolute value of all the above was taken, in order to calculate a total for it. The total value was calculated to be 3.5965. Each variable was then divided by the total, to make it into a weighted variable. The table below shows the calculated weight for each variable.

	Sig	Absolute Value	Weight
a4 Adjuvant therapies are important in managing pain.	.661	0.6608	0.1837
a6 The provisions of palliative care require emotional detachment.	.568	0.5685	0.1581

a14 Terminally ill patients should be encouraged to have hope against all odds.	.560	0.5601	0.1557
a13 Terminally ill patients have the right to choose “Do not resuscitate” (DNR).	.551	0.5506	0.1531
a9 The use of placebos is appropriate in the treatment of some types of pain.	.393	0.3926	0.1092
a7 During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	.150	0.1498	0.0416
a8 The philosophy of palliative care is compatible with that of aggressive treatment.	.145	0.1447	0.0402
a1 Do you know the definition palliative care?	.113	0.1128	0.0314
a10 Opioid (Morphine) is not an effective analgesic for the control of chronic pain.	.101	0.1012	0.0282
a12 Manifestations of chronic pain are different from those of acute pain.	.062	0.0618	0.0172
a11 The accumulation of losses renders burnout Inevitable for those who work in palliative care.	-.022	0.0216	0.0060
a3 The extent of the disease determines the method of pain treatment.	-.058	0.0577	0.0161
a2 Palliative care is only appropriate in situations of a downhill trajectory or deterioration in conditions.	-.093	0.0933	0.0259
a5 Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	-.121	0.1209	0.0336
Total		3.5965	

Then a new variable was computed, Knowledge, by multiplying each question (a1 to a14) with its weight, and adding them all together. Note that positive correlations are added, and negative correlations are subtracted. Given that the answers for knowledge related questions are either Yes or No, coded as 1 or 2, the values obtained for the new variable are between 0-2, in order to make it out of 1, the entire equation is divided by 2.

The following equation was used to calculate Knowledge, given that the weighting value added here is a round figure, but the whole figure was used in SPSS:

$$\begin{aligned}
\text{Knowledge} = & ((0.183 * A4) + (0.158 * A6) + (0.156 * A14) + (0.153 * A13) \\
& + (0.109 * A9) + (0.042 * A7) + (0.04 * A8) + (0.031 * A1) + (0.028 * A10) \\
& + (0.017 * A12)) - ((0.006 * A11) + (0.016 * A3) + (0.093 * A2) \\
& + (0.034 * A5))/2
\end{aligned}$$

The new variable, Knowledge, results are now transformed onto a scale, where all values .75 and higher, are coded as Good Knowledge, and all other values, below 0.75 are Poor Knowledge.

Association between Socio-demographic variables and Health Providers Knowledge towards PC

- Gender

Gender	Knowledge	
	Good	Poor
Male	23 (43 %)	30 (57%)
Female	60 (59%)	42 (41%)

Females working at CBH have better knowledge on palliative care than males, where 60 females and 23 males only have good knowledge on PC. On the other hand, (57%) of males have poor knowledge on palliative care, and (41%) of women.

- Age

Age	Knowledge	
	Good	Poor
< 30	24 (56%)	19 (44%)
30 – 39	15 (44%)	19 (56%)
40 – 49	24 (52%)	22 (48%)
50 +	20 (63%)	12 (37%)

Result number 2: Health workers age 50 years or more have better knowledge in palliative care, reaching (63%), and (56%) of those of 30 years old or less, also have good knowledge. There is a gap in palliative care knowledge for those in the age groups between the mentioned above, where

(56%) of those between 30-39 years old have poor knowledge in PC, as well as (48%) of those 40-49 years old.

- Level of Education

Education	Knowledge	
	Good	Poor
Diploma	26 (50%)	26 (50%)
Bachelor	45 (61%)	29 (39%)
Master degree and higher	12 (41%)	17 (59%)

As there was no health provider with lower a degree lower than a Diploma, the table only shows 3 levels. (61%) & (50%) of those who have a Bachelor or a Diploma, respectively, have good knowledge in palliative care, and only (41%) of those whom have a Masters' degree and higher.

- Profession

Profession	Knowledge	
	Good	Poor
Physician	9 (43%)	12 (57%)
Nurse	51 (54%)	43 (46%)
Social Worker	5 (83%)	1 (17%)
Laboratory Technologist	7 (78%)	2 (22%)
Radiologist	2 (50%)	2 (50%)
Physiotherapist	6 (100%)	0
Pharmacist	0	2 (100%)
Administration Staff (Managers)	1 (11%)	8 (89%)
Dietary Services Staff	2 (50%)	2 (50%)

The top three professions with good knowledge on palliative care are Physiotherapist (100%), Social Workers (83%), and Laboratory Technologist (78%). The rest of Profession groups have less than (55%) of them with good palliative care knowledge, with the highest three with poor palliative care knowledge are Pharmacists (100%), Administration Staff (Managers) (89%), and Physicians (57%). It should be noted that (46%) of nurses also have poor knowledge on PC.

- Years of Experience

Experience (Years)	Knowledge	
	Good	Poor
1 – 4	23 (54%)	20 (46%)
5 – 9	15 (50%)	15 (50%)
10 – 14	11 (52%)	10 (48%)
15 +	34 (56%)	27 (44%)

As for years of experience, good knowledge on Palliative care doesn't seem to exceed (56%) for all the groups above, which is attributed to health workers with 15+ years of experience, with the lowest percentage (50%) of good knowledge is for those who have 5-9 years of experience.

Computing “Attitude” Indicator

Attitude was calculated as an indicator through factor analysis and weighing, in order to compare it to the socio-demographic data obtained. The same method above was used to calculate this indicator, but using questions regarding Attitude, B1 -B25.

b20 I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	.848
b21 I would be uncomfortable talking about impending death with the dying Person.	.811
b19 I am afraid to become friends with chronically sick and dying patients.	.593
b25 I would not want to be assigned to care for a dying person	.401
b9 The health providers should not be the one to talk about death with the dying person	.325
b12 It is difficult to form a close relationship with the family of a dying member.	.321
b18 When a patient asks, “health provider, am I dying?” I think it is best to change the Subject to something cheerful.	.321
b6 The length of time required to give palliative care to a dying person would frustrate me	.308
b24 I would feel like running away when the person actually died.	.264

b16 Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.	.256
b8 Family should maintain as normal an environment as possible for their dying member.	.123
b7 Families should be concerned about helping their dying member make the best of his/her remaining life	.093
b14 Palliative care for the patient's family should continue throughout the period of grief and bereavement.	.068
b17 Palliative care should extend to the family of the dying person.	.011
b2 As a patient nears death; the health providers should withdraw from his/her involvement with the patient.	.001
b13 There are times when death is welcomed by the dying person	-.018
b5 Family members who stay close to a dying person often interfere with a professionals' job with the patient.	-.026
b4 It is beneficial for the chronically sick person to verbalize his/her feelings	-.028
b10 The family should be involved in the physical care of the dying person.	-.076
b23 Death is not the worst thing that can happen to a person.	-.104
b1 Palliative care is given only for dying patient	-.125
b3 Giving palliative care to the chronically sick patient is a worthwhile learning experience	-.125
b15 The dying person and his/her family should be the in-charge decision makers	-.138
b22 It is possible for health providers to help patients prepare for death.	-.180

The top 5 values, shaded in light red, are of the highest correlation, the cells shaded in light blue represent questions with the lowest correlation to Attitude, as the numbers show, disregarding the sign. As for positive and negative significance, majority of questions have a positive significance, except for the bottom 9 questions, with negative values, which represent negative significance on Attitude. The absolute value of all the above was taken, in order to calculate a total for it. The total value was calculated to be 5.5641. Each variable was then divided by the total, to make it into a weighted variable. The table below shows the calculated weight for each variable.

	Sig	Absolute	Weight
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		Value	
b20 I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	.848	0.8478	0.1524
b21 I would be uncomfortable talking about impending death with the dying Person.	.811	0.8109	0.1457
b19 I am afraid to become friends with chronically sick and dying patients.	.593	0.5935	0.1067
b25 I would not want to be assigned to care for a dying person	.401	0.4014	0.0721
b9 The health providers should not be the one to talk about death with the dying person	.325	0.3246	0.0583
b12 It is difficult to form a close relationship with the family of a dying member.	.321	0.3213	0.0577
b18 When a patient asks, "health provider, am I dying?" I think it is best to change the Subject to something cheerful.	.321	0.3209	0.0577
b6 The length of time required to give palliative care to a dying person would frustrate me	.308	0.3080	0.0554
b24 I would feel like running away when the person actually died.	.264	0.2642	0.0475
b16 Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.	.256	0.2564	0.0461
b8 Family should maintain as normal an environment as possible for their dying member.	.123	0.1230	0.0221
b7 Families should be concerned about helping their dying member make the best of his/her remaining life	.093	0.0930	0.0167
b14 Palliative care for the patient's family should continue throughout the period of grief and bereavement.	.068	0.0683	0.0123
b17 Palliative care should extend to the family of the dying person.	.011	0.0106	0.0019
b2 As a patient nears death; the health providers should withdraw from his/her involvement with the patient.	.001	0.0006	0.0001
b13 There are times when death is welcomed by the dying person	-.018	0.0178	0.0032
b5 Family members who stay close to a dying person often interfere with a professionals' job with the patient.	-.026	0.0257	0.0046
b4 It is beneficial for the chronically sick person to verbalize his/her feelings	-.028	0.0281	0.0051
b10 The family should be involved in the physical care of the dying person.	-.076	0.0763	0.0137

b23 Death is not the worst thing that can happen to a person.	-.104	0.1036	0.0186
b1 Palliative care is given only for dying patient	-.125	0.1251	0.0225
b3 Giving palliative care to the chronically sick patient is a worthwhile learning experience	-.125	0.1253	0.0225
b15 The dying person and his/her family should be the in-charge decision makers	-.138	0.1376	0.0247
b22 It is possible for health providers to help patients prepare for death.	-.180	0.1802	0.0324
	Total	5.5641	

Then a new variable was computed, Attitude, was computed by multiplying each question (b1 to b25) with its weight, and adding them all together. Note that positive correlations are added, and negative correlations are subtracted. Given that the answers for Attitude related questions are a range from Definitely Agree to Definitely Disagree, which is a 5 point scale, it is divided by 5, to ensure that scale is from 1. The following equation was used to calculate Attitude, given that the weighting value added here is a round figure, but the whole figure was used in SPSS:

$$\begin{aligned}
\textit{Knowledge} = & ((0.152 * B20) + (0.146 * B21) + (0.106 * B19) + (0.072 * B25) \\
& + (0.058 * B9) + (0.058 * B12) + (0.058 * B18) + (0.055 * B6) \\
& + (0.48 * B24) + (0.046 * B16) + (0.022 * B8) + (0.017 * B7) \\
& + (0.012 * B14) + (0.002 * B17) + (0.0001 * B2)) - ((0.003 * B13) \\
& + (0.005 * B5) + (0.005 * B4) + (0.014 * B10) + (0.019 * B23) \\
& + (0.023 * B1) + (0.023 * B3) + (0.025 * B15) + (0.032 * B22))/5
\end{aligned}$$

The new variable, Attitude, results are now transformed onto a scale, where all values that are .5 and above are of favorable attitude, and those less than .5 have an unfavorable attitude towards palliative care. The result comparing those two with the socio-demographics of this study are seen below.

Association between Socio-demographic variables and Health Providers Attitude towards

PC

- Gender

Gender	Attitude	
	Favourable	Unfavourable
Male	14 (26%)	39 (74%)
Female	50 (49%)	52 (51%)

(49%) of female health workers have a favorable attitude towards palliative care, but only (26%) of males do. With 39 male health workers, and 52 females with unfavorable attitude towards PC, which represents (74%), and (51%) of male and female health workers, respectively.

- Age

Age	Attitude	
	Favourable	Unfavourable
< 30	19 (44%)	24 (56%)
30 – 39	13 (38%)	21 (62%)
40 – 49	17 (37%)	29 (63%)
50 +	15 (47%)	17 (53%)

(63%) of those 40-49 years old have an unfavorable attitude towards PC, and (62%) of those 30-39 years old. Similarly, (56%) of those less than 30 years old, and (53%) of 50+ years old also have an unfavorable attitude.

- Level of Education

Education	Attitude	
	Favourable	Unfavourable
Diploma	27 (52%)	25 (48%)
Bachelor	29 (39%)	45 (61%)
Master degree and higher	8 (28%)	21 (72%)

The higher the level of education, the higher is the unfavorable attitude towards palliative care, with (72%) of those with master's degree and higher have unfavorable attitude. (61%). 45 health workers, with a Bachelor degree, have an unfavorable attitude towards PC, they represent 2/7 health workers at CBH. As for those with a Diploma, (52%) of them have a favorable attitude towards PC.

- Profession

Profession	Attitude	
	Favourable	Unfavourable
Physician	5 (24%)	16 (76%)
Nurse	45 (48%)	49 (52%)
Social Worker	3 (50%)	3 (50%)
Laboratory Technologist	5 (56%)	4(44%)
Radiologist	2 (50%)	2 (50%)
Physiotherapist	1 (17%)	5 (83%)
Pharmacist	0	2 (100%)
Administration Staff (Managers)	3 (33%)	6 (67%)
Dietary Services Staff	0	4 (100%)

When attitude is categorized by profession, only 4 out of 9 professions had (48%) and more of health providers with favorable attitude, with the highest being (56%) of Laboratory Technologist with favorable attitude. (50%) of both social workers and radiologist have a favorable attitude, and (48%) of nurses. As for the rest profession groups, 0 pharmacists and dietary staff have a favorable attitude. (83%), (76%), and (67%) of physiotherapists, physicians, and administration

staff have an unfavorable attitude towards palliative care. These are alarming results, given that these 3 professions are main channels for most patients.

- Years of Experience

Experience (Years)	Attitude	
	Favorable	Unfavorable
1 – 4	16 (37%)	27 (63%)
5 – 9	12 (40%)	18 (60%)
10 – 14	8 (38%)	13 (62%)
15 +	28 (46%)	33 (54%)

As for years of experience, (46%) and (50%) of those with experience of 15+ years, and 5-9 years, respectively have a favorable attitude towards PC. At the same time, (63%) of those with 1-4 years of experience, and (62%) of those with 10-14 years of experience have an unfavorable attitude towards palliative care.

Discussion of the Results

When looking the descriptive results (presented in percentages) for the individual questions (that represented meaningful aspects of the constructs Knowledge and attitude, these showed relatively some knowledge on palliative care, a general favorable attitude, as well as good knowledge of practice. But when Knowledge and Attitude were computed as a new variable, compared to socio-demographic results, and were split into different categories, the general results showed that there is a good knowledge on palliative care at CBH. Yet, when categorized the results by profession, the knowledge of the administration staff was not significant. As for attitude towards PC, an unfavorable attitude dominated most of the results among all socio-demographics categories. The highest percentages with a favorable attitude towards PC included the following categories: laboratory technologists of 56%, nurses and radiologists of 50%, and those holding a Diploma degree of 52%. All other categories recorded less than 50% including social workers which mean that even for social workers the favorable attitudes toward PC was not significant.

These results are considered important to discuss in which one alarming result for me was regarding the Physicians who have generally showed unfavorable attitude toward PC and demonstrated less knowledge given the fact of the importance of the role of the physicians in providing information, ease and comfort for the family and the patients during this critical time of life.

Considering the literature review we discussed earlier, it could be debated that according to theory of change “when we add a new input, we will get a new output” (Lindgren, 2015), this research has also confirmed this model. Introducing the concept through this research has showed that some attitudes were positively influenced as a result of the new knowledge introduced. The study discussed some specific practices that were introduced to different medical professionals, who started to be familiar to them after introducing the concepts. In other similar studies that assessed KAP of the nurses like the study of the Menofia hospital in Egypt, quasi study showed improvement in knowledge, attitude, and practice of nurses after they improved the knowledge of the Nurses regarding Palliative care.

Regarding physicians, there have been so many studies that were conducted to assess the KAP of the physicians, for example a European collaborative study was conducted for physicians across 7 countries, Belgium, Denmark, Italy, Netherlands, Sweden, Switzerland, and Australia as well. (Miccinesi, et al., 2005). Physicians from different specialties that were seen to be involved in end-of-life care were asked to participate Training in palliative care was also associated to the perspective of the participants of non-treatment methods, where physicians with training were more supportive of palliative care. Finally, physicians who have attended to more terminally-ill patients were also more supportive of palliative care than physicians who deal with less terminal diseases (Miccinesi, et al., 2005). This study has shown that physicians who have poor knowledge regarding Palliative they were resistance to the concept and refused to refer their patients to Palliative care. One possible explanation could be related to the fact that physicians

might feel that when they send their patient to palliative care that could mean that the Physician is failed in providing cure to his/her patient and they might find that as failure in their role. Considering the studies that looked at the role of the social worker which was mentioned in the literature review, One of the studies we discussed was Jones (2005) who conducted a study regarding current practice methods of social workers providing end-of life treatment in the pediatric oncology department with the aim of identifying their best practice or ideal role within the sector. This study assumed that social workers and palliative careers have very similar job description, where the social worker can cover multiple palliative care roles such as psychologist, advisor, family consoler...etc.

Another model I discussed in the literature review which I find very powerful, is the model of Kerala in India (Prem, et al., 2012) which started as a result of a community need where volunteers reached to government and the health system to implement care. As a community model for Palliative care, this model take into consideration the needs of the community and build on them an approach for health care that could be adopted from the health system. Here human needs basically of sick children and their families that mainly focus on the psychosocial, spiritual and cultural aspects are addressed through volunteers who were trained to meet the unmet needs of these sick children and their families which is started from the community down-top approach. This approach has showed a big success in the different communities of India. Regarding our case study of Caritas, this approach could be beneficial. If health care providers especially nurses and Physicians and social workers are more aware of the needs and are provided with the required training and education they could train volunteers in the community to provide such care for the patients and their families in their communities when they are not in the hospital. Raising awareness through education and training in this field improve the kinds of the services that could be provided within the system and considering the cultural backgrounds of the people in the Hospital and in the community, such system could be efficient in its costs since

it could be depending in trained volunteers. Moreover, it is worth to mention, that most of the studies that mentioned in this research are concentrated on physicians and nurses of the pediatric palliative care field, and they didn't concentrate on other professions, but if we look at the practice of PPC we emphasize that it needs a multi-disciplinary team to deal with patients and their families. Each can do his/her role within the team. I believe that PPC should not just concentrate on the medical situation of the sick child and his/her family, but it also should concentrate on all the aspects, Social, psychological, spiritual and cultural. I also believe that Nurses and physician can't cover all these aspects alone, therefore a qualified a multi-disciplinary team is needed to deal with these chronically cases to cover all the aspects.

In spite that the Pediatric Palliative care (PPC) is a new approach in our area and despite the hard-political situation the Palestinians are living under which entails limited resources, I found that (Shawawreh & Khleif, 2011) and (Zeina, 2012) studies highlighted the possibility of introducing Palliative care in North Palestine despite limited resources. What I find important when examining these studies are the recommendations that focused on the importance of concentrating on the multi-disciplinary team to apply the PC within the system of the Hospital.

However, the results of this research also concluded those recommendation through emphasizing the necessity of applying the PPC in the system and the culture of Caritas Hospital especially that the results highlighted the presence of moderate knowledge among the professions, with unfavorable attitude and a moderate practice. Finally, I have found that PPC system is consistence with the mission and the vision of Caritas.

Evidence from the literature has found that palliative care services improve quality of life for children with life-limiting illness and their families in the areas of the child's emotional well-being and parental perception of preparation for the child's end of life. Future research should include high quality studies with larger sample sizes and control groups, and include children's

perspectives-from both patients and siblings-to give a more complete picture of how best to improve their quality of life.

In-depth discussion

Regarding to my research questions I tried to highlight the extent to which the findings answered the questions according to the status of knowledge, attitudes and practices of Caritas health providers and how the social workers can be involved in implementing in PPC unit.

Furthermore the literature highlighted the role of Gender in this matter. The findings showed that the female nurses and physicians are more emotional than the male ones and this result is in consistence of the results of my research which found that females at CBH have a better knowledge on Palliative care than males do, where 60 females and 23 males only have good knowledge on PC. On the other hand, 57% of males and 41% of females have poor knowledge on palliative care. Moreover, the study showed that 49% of female health workers have a favorable attitude towards palliative care, but only 26% of males do. While 39 male health workers, and 52 females with unfavorable attitude towards PC, which represents 74%, and 51% respectively. An explanation of these results could be explained from the cultural point of view that addresses the way men and women are taught to deal with feelings and emotions in the Palestinian culture, were women are considered to be better able to deal with sensitive and emotional issues rather than men, while men are reluctant when it comes to express their emotions especially in issues that are related to sickness and death, as they have to show that they are strong most.

Looking into the **age variable**, the results showed that health workers over 50+ years old and those 30- years old have better knowledge on palliative care recording 63%, and 56% respectively. Age groups between 30-39 (56%) and 40-49 (48%) have poor knowledge about PC. This shows that there is a gap in palliative care knowledge among the age categories mentioned above; health workers of 50+ years, and -30 have a good knowledge of palliative care, but health

workers whom are between 30-39 and 40-49 years old have less or poor knowledge. Additionally, the study showed that As for years of working experience, good knowledge on PC doesn't seem to exceed 56% for all health workers with 15+ years of experience, and lower percentage is marked of 50% for those who have 5-9 years of working experience.

It could be argued that the more years of experience the health providers acquire during their working life, the more they are knowledgeable of the concept of PC, and this was clear in the age category of 50+ years in which the chances that they get exposed to aspects of Palliative Care at the hospital during their long career life are increasing with the time. On the other hand, newly graduated workers -30 years old, have also good knowledge on PC given that might have been exposed to and taught these concepts of PC through their education.

As for Poor knowledge on PC that was found between the ages of 30-49, this is an alarming sign that we have to take care of after this study, to help and offer them the chance to improve their knowledge and skills by capacity building programs, study tour to institutions offering PC in the region.

When it comes to **the level of education**, the study found that health providers with Diploma (50%) have better attitude towards PC. While those holding BA (61%), MA (41%) and higher have unfavorable attitude towards PC. One could argue that those who have higher education consider themselves as better qualified and confident in their education, or are fixed in their prescribed roles so they don't see the need to add this practice to their work, or they don't see the connection of it to their profession.

As for the professions, the study showed that, Social workers (83%), Physiotherapy (100%), and Laboratory Technologist(78%), are having a good knowledge of palliative care, the ones whom are having a poor knowledge in palliative care are the Pharmacists(100%), Administration staff (89%), and physicians (57%). On the meanwhile 46% of nurses whom are the majority of the health providers' population, have showed poor knowledge on PC. One could argue that these

results emphasize that the concept of PC is a new concept that is not fully explored and explained in the hospital setting. These results are considered important to address a policy change at the hospital level and especially among the administration to push toward raising the awareness of this concept and the importance of understanding it.

The Role of Social work in Palliative Care

The analysis of the answers of the social workers show some contradictory results, when answering the main question in the Knowledge scale whether they know the Palliative Care the majority of social workers seem to have good knowledge on PC, with 83.3% having a favorable attitude towards PC, and 83.3% have good knowledge on practice of PC. These results have showed that social workers seem very favorable to the concept of palliative care, and have a general understating of the concept, but when the attitude and Knowledge scale is taken in further analysis as indexes, social workers have not showed significant results in their knowledge of Palliative care. Since the tasks of Palliative care was detailed in those instruments, and lack of the significance of the results for social workers might be referred to the fact that social workers might have general knowledge of Palliative care but are not aware of their role in this practice, and are not able to see a separate task for them in the hospital from the tasks and roles that they already performing in their practice. That is also showed that in the detailed discussion of their roles in the focus group discussion, they have demonstrated a better idea in how they could integrate their role in this regard with other professions at the hospital, In some cases, better than administration staff, nurses, and physicians. They have a better understanding of it, as well as better knowledge on practice.

To explore the different dimensions of the social work's role regarding Palliative care the focus group of the five female social workers at Caritas Baby Hospital was able to shed lights on their knowledge on palliative care, their attitude and their practice and explore the different

dimensions that were not clear at the survey. All five social workers agreed that the concept of palliative care is new, and during their work at the hospital, they started to be familiar with it. This focus group flagged important recommendations.

Going back to the Theory of change which is based on the concept that when a new input is added (targeting social workers), a new output is realized which is clear in this study that social workers are an essential part of PC service. That means when social workers or other professionals are introduced through training workshops, supervision, in-house training sessions...etc. to the concept and its manifestations, then a change in knowledge will improve the attitudes and will be manifested on the practices. What makes this study unique and different from other studies conducted in Palestine, is that it targeted social workers and not only physicians and nurses as other studies and it raised the importance of social workers' role in palliative care.

This study tries to shed lights on a new concept, despite that the health providers and social workers have expressed that they are familiar with it, but this study has showed that a lot of work should be done to understand this vital service at CBH where chronic and uncured illnesses of children are a daily reality at the hospital but a lot of discussion is needed to start to initiate changes in policy and practice in order to understand better how we can improve the quality of life for our patients and their families during this critical and detrimental part of their lives and existence. An addition of this study would be interviewing the families and shed lights to their needs regarding this matter.

Conclusion

The study above studied Knowledge, Attitude, and Practice of Palliative care of health providers or workers working at Caritas Baby Hospital. The results mainly show good general knowledge on PC, with minor sections with low knowledge, but also the respondents seem to have a moderate attitude towards PC, where regarding pain management, or relation with patient and their family, respondents seem to have an uncertain or unfavorable attitude. Lastly regarding practice, respondents generally seem to have good practice of PC, where they seem to understand how PC is to be practiced.

Nevertheless, when the data was distributed according to the socio-demographics of the respondents, the results seem to be a bit different. Although the majority of respondents have good knowledge on PC, Administration Staff, Nurses, and physicians, whom are important part of the health providing network, seem to have the highest percentage of poor knowledge. This was also reflected when categorizing attitude into favorable and unfavorable attitudes towards PC, where there three professions, in addition to physiotherapists and social workers, have the highest percentages of unfavorable attitude towards palliative care, this may seem be seen as an alarming result, given that these professions are the main contact points for patients and their families at CBH. Lastly, when assessing knowledge on practice of palliative care at CBH, the results seem to be more alarming than the previous, where there is low good knowledge on practice at CBH, for all socio-demographics, except for social workers, whom seem to have the highest percentage on practice of PC, where (83.3%) of social workers have good knowledge on practice.

To answer the study question, the majority of social workers seem to have good knowledge on PC, (83.3%) have a favorable attitude towards PC, and lastly (83.3%) have good knowledge on practice of PC. These results prove that social workers seem very capable of working in palliative

care, in some cases, better than administration staff, nurses, and physicians. They have a better understanding of it, as well as better knowledge on practice.

In depth discussion group for Social Workers

A focus group was conducted with all five female social workers at CBH. Open ended questions which guided the group discussion included their role at Caritas Baby Hospital, the acceptance and understanding of their role from the other health providers, their knowledge of the concept of PC and their experience and their recommendations. This Focus group targeted social workers specifically since the researcher tried to answer the following research question: What role do social workers play within pediatric palliative care? How can social workers integrate themselves better into the pediatric palliative care team?

A coding was done for the interview protocol and the results of the coding of the focus group were categorized in six categories.

1. Support and acceptance:

- One of the social workers' roles is to support families when dealing with death, or an ill child, as a social worker can help with ease and preparedness to acceptance of the situation, as well as provide certain comfort by being around the mother and or the family, given that the psychological, social and spiritual factors are the main factors of the process. One of the social workers said: "We are here to facilitate and to support the families and their children during their staying at our Hospital, I believe that these families don't need our empathy or sympathy, they need a true care, acceptance and understanding their medical and social situation".
- Doctors mainly accept and understand the role of a social worker within the team, and the hospital, although they might not always cooperate fully with the social workers, by contacting them or informing them of certain conditions about the

patient, one of the social workers said: “I impose myself and my role as a social worker, I don’t wait the request or the permission of the doctor to be involved in dealing with children and their families.” The entire social workers agreed with her, and assured what they are doing.

2. Knowledge of the concept of the Palliative care:

- Palliative Care was a relatively new term to all social workers, although they were practicing it in certain ways, they never knew the term. One of the social workers mentioned that “experience plays a part in this”. Nevertheless, social workers have agreed that they haven’t heard of any training in PC in the region, and no references to use within the Middle East region, although there are other foreign sources.

One of the social workers maintained that she has been to a hospital in Belgium, with a full PC team, where they explained what PC was, how to practice it, and so on. She said there were similarities in procedures followed in the hospital in Belgium, and CBH in terms of transfer of information and preparedness for any reaction from the family. The main difference between the two hospitals is lack of equipment and facilities at CBH for PC. As a researcher, I want to flag that though Palestinians are living in critical social, political, economic, and psychological situations, and most of our institutions do fundraising from the abroad to survive, and in spite of all of this hardship in life and lack of equipment, and space at CBH, yet we are doing the same role of the other social workers that have more facilities.

3. Role of social workers in reducing the gap between families and doctors:

- The social worker was asked to describe the emotions of the family at these hospitals during the time when the child is transferred to a PC unit; she elaborated that this is the time when the social workers’ role is most direct and critical, where

the social workers is not only telling the parents of a patient on his/her condition, but they also deal directly with the psychological factor of everyone involved, which is a hard task to do. This is done either in private rooms at the hospital, or at home, where there are teams who provide group and individual sessions with the family to increase the psychological and social support needed. She said: "One of the goals of a social worker within these situations is to decrease the gap between the family and the patient".

- CBH generally decides on informing the patient of his/her disease, for children less than 14 years old, this is to make sure that patient has correct information, and for him/her to be a part of the process. One of the social worker said: "this process can't be done without the involvement of the social workers".
- The group agreed on the role of social workers in palliative care, as a role for communication and networking between the doctor, the patient, and the family, as well as provide psychological and social support for this network, and lastly to coordinate and communicate with the patient, in order not to harm him/her. The group also pointed out that there is no place at the hospital where social workers can privately and confidentially speak with a patient or his family.

4. The importance of self-development:

- All social workers stressed on the importance of improving their skills regarding anything related to their work as social workers at a hospital. They are equipped to understand medical terms, and to understand their weaknesses and strengths, yet specialists here learned that through experience, one of the social worker said: "I learned most of the medical terms during my participating on the daily round with the doctors, I used to ask about anything that I don't understand, besides I have a

copy book, I used to write down all the new concepts and terminologies and search about the definitions through the internet, not like in Europe for example, where it is based on foundations and studies". Social workers agreed that they need to learn and develop themselves and their medical terms, attend medical conferences, read articles, and so on. Social workers are capable of keeping up with the doctor and medical terms, as they are specialists by experience.

5. Religious and spiritual side:

- As for the spiritual/religious side, they have agreed that religious figures are like a reference point for social workers. But given that in this society, religious figures play an important role, their part become supportive of that of a social worker, where their roles are similar, and they can tackle things from a spiritual perspective, to reduce the pain of the patient and the family.

6. Burn-out:

- when the issue of the psychological impact on the social workers as a result of dealing with continuous death, incurable illnesses or difficult cases, was addressed, social workers clearly expressed that they might feel emotional weariness and burn out, and it can become a burden on them to some extent, they expressed the need for supervisor to help and support them with their work. "We take the negative energy from the patient, and give him positive energy, that's why we need someone to support us" as explained by one of the social workers".

Another one said:

“We need skills and capacity building because knowledge is a continuous learning and accumulated process especially in medical terms that a social worker acquires with experience, morning rounds with the doctors, as well as his/her presence at the hospital. Universities should also offer a course in coordination with the hospital and ministry of education, so chronically ill children can continue their education, given that there is no attention to this topic, which has a negative effect on the child’s psychology”.

Recommendations

Regarding the total health work force at Caritas Baby Hospital, given that their knowledge on PC is relatively good, two main recommendations are to be given: firstly, the attitude of health workers should be tackled, by introducing the benefits of PC, and giving case studies of how it works, and it has in the past, their attitude should show some change. The second recommendation is related to practice, where proper palliative care practice methods should be taught, especially for health workers in direct contact with patients and their families. This is because poor knowledge on PC practice seems to be more dominant at CBH. Furthermore, CBH should try to provide some facilities for palliative care, or designate certain areas for PC patients, families, and health providers, by offering a space for them where they can communicate privately, and feel safe.

As for social workers, it is recommended that their involvement with palliative care at CBH is to be increased; this is because the majority seems to have good knowledge, favorable attitude, and good knowledge on practice. Off course, as past studies have shown, social workers have low medical knowledge, thus this should be tackled by giving them basic medical training for their own comfort when there is an increase in their role and involvement.

Conclusion and Recommendations of the Study

Pediatric Palliative care (PPC) is a medical field at its infancy in the region, especially in Palestine, and it is a multidisciplinary effort that requires the support of hospital administration. The main findings of this study showed that all medical professionals understand the need to integrate palliative care into the health system and it is a medical tool that can be used to improve the quality of care for terminally sick children and their families.

The aim of this study was to assess the Knowledge, Attitudes, and Practice (KAP) of health providers providing pediatric palliative care at CARTIS Baby Hospital (CBH). The results of this study showed good general knowledge on PPC, with minor sections at CBH with low knowledge, but also the majority of medical staff seemed to have a moderate understanding of the need of PPC, in regards to pain management, but in regards to building a solid relation with patients and their families, CBH healthcare professionals seem to have an uncertain or unfavorable attitude. Lastly regarding practice, CBH respondents generally seem to have good practice of PC, where they seem to understand how PC is practiced.

Based on the results of this study, CBH healthcare providers seemed to have a good theoretical knowledge of pediatric palliative care, including administrators, doctors, nurses, and pharmacists, but this knowledge is not sufficient to start providing quality palliative care at CBH. According to the results, only CBH social workers seemed to have good theoretical and practical knowledge of PC, with 83.3% favorable attitude towards PC, and a similar 83.3% practical knowledge that allow them to perform pediatric palliative care. These results prove that social workers seem very capable, in some instance, even better than administration staff, nurses, and physicians. They have a better understanding of it, as well as better practical experience. Based on these results, the following recommendations are presented:

Specific Recommendation for CBH

- 1- Improve the attitude of CBH Healthcare providers by teaching them the benefits of PC, providing space to present case studies, learn about the importance of PC and how it can improve the quality of care.
- 2- Provide opportunities for CBH Healthcare professional to practice PC and shadow PC nurses and doctors at other advanced hospitals in the region and international.
- 3- Receive intensive training on the pharmaceuticals and medication used for palliative care. In addition, to when and how these are administrated to the patients.
- 4- Dedicate a small section inside CBH hospital, 2-3 beds, for palliative care. Dedicating a child-friendly space for palliative care patients will have a positive influence on the journey of these sick children.
- 5- Improve the environment and the hospital settings in line with PC requirements, such as having a private space for the families with their children, allowing enough and private space for the family to openly and freely discuss own values and believes, either alone or with presence of a social worker or palliative care team.
- 6- To increase the involvement of skilled social workers at CBH to provide support to palliative care patients, since the social work team seemed to have a sufficient knowledge, favorable attitude, and good experience dealing with death and talking with children.
- 7- Allow the parents to be part of the decision making, by involving the parents at each step of the way.

Based on the literature, palliative care in the Middle East is also considered as an emerging and there is not a lot of functioning systems in the region. Moreover, some countries in the region has taken individual initiative to advance their medical services, such as King Hussein Cancer Center

(KHCC) but at a national level, Jordan has still a long way to go, in addition to many Arab Countries. Hence, based on the literature review, general recommendations are presented below:

General Recommendations

- 1- Work on changing the culture in the hospital setting to accept and integrate pediatric palliative care in Palestine and allow healthcare professionals realize the need for palliative care.
- 2- Offer training opportunities to doctors, nurses, social workers, pharmacists and hospital administration. The training could include conferences, rotation and field visits to more advanced facilities with palliative care.
- 3- Host regular in-house workshops and seminars to all involved medical professionals to develop understanding of palliative care and its importance and define roles and responsibilities of each medical field e.g. physicians, nurses, social workers...etc.
- 4- Develop the referral system inside the sections in the hospitals and be aware of other PPC partners in the area to build a sense of a network for shared cases and shared learning.
- 5- Develop medical protocols and guidelines for multidisciplinary team to be able to handle palliative care patients with best practices available.
- 6- Search and learn about different models of palliative care services that could complement the current experience in the region.
- 7- Develop regional networks for pediatric palliative care professional among Arab Countries to allow for opportunities of shared learning and experiences to improve palliative care in the region.

References

1. Ami, S. & Yaffe, A. (2015). **Palliative Care in Israel: The Nursing Perspective.** *Journal of Palliative Care & Medicine.*
2. Anon.2016. *Adult vs. Pediatric Palliative Care.* Retrieved from <https://getpalliativecare.org/whatis/pediatric/>
3. Ayed, A. et al. (2015). **The Nurses' Knowledge and Attitudes Towards the Palliative Care.** *Journal of Education and Practice*, 6(4), pp. 91-99.
4. Caritas Baby Hospital, C.(2013). *Our History and Innovations.* Retrieved from: <http://www.cbh.ps/index.php/about-us/our-history-and-innovations> [Accessed 17 11 2016].
5. Centeno, C. et al., (2007). *EPAC Atlas of Palliative Care in Europe.* s.l.:IAHPCPress.
6. COMECE, 2016. *Opinion of the Working Group on Ethics in Research and Medicine on Palliative Care in the European Union*, Belgium: COMECE.
7. CSI & University of Minnesota (2016). *A Consensus Operational Definition of Palliative Care in Action*, s.l.: Institute for Clinical Systems Improvement and the University of Minnesota.
8. Evan E, Calonico E, Tan B, and Zeltzer L, (2012). **A Qualitative Approach to Understanding Quality of Life in Pediatric Palliative Care.** *Journal of Palliative Care & Medicine*, ISSN: 2165-7386.
9. Feudtner, C. et al. (2013). **Hopeful Thinking and Level of Comfort Regarding Providing Pediatric Palliative Care: A Survey of Hospital Nurses.** *Pediatrics*, pp. e186-e192.
10. Frommelt, K. H. (2003). **Attitudes toward care of the terminally ill: an educational intervention.** *Am J Hosp Palliat Care.* Jan-Feb;20(1):13-22.
11. Green, C. E. (2001). **Can qualitative research produce reliable quantitative findings?** *Field Methods* 13(3), 3-19.
12. Hausmann-Muela, S., R. J. Muela and I. Nyamongo. (2003). **Health-seeking behaviour and the health system's response.** *DCPP Working Paper* no. 14.
13. Huijjer, H.-S., Dimassi, H. & Abboud, S. (2009). **Perspective of Palliative Care in Lebanon: Knowledge, Attitude, and Practices of Medical and Nursing Specialties.** *Palliative and Supportive Care*, pp. 339-347.
14. Jones, B. L.(2005). **Pediatric Palliative and End-of-Life Care.** *Journal of Social Work in Endof-Life & Palliative Care*, Volume 14, pp. 35-62.

15. Jones, P. M. & Carter, B. S. (2010). **Pediatric Palliative Care: Feedback From the Pediatric Intensives Community.** *American Journal of Hospice & Palliative Medicine*, 27(7), pp. 450-455.
16. Khleif, M. & Dweib, A. (2015). **Palliative Care and Nursing in Palestine.** *Journal of Palliative Care & Medicine.*
17. Knapp, C. A. et al. (2011). **Pediatric Nurses' Attitudes Toward Hospice and Pediatric Palliative Care.** *Pediatric Nursing*, pp. 121-126.
18. Knapp, C., Madden, V., Fowler-Kerry, S. & (Editors) (2012). **Pediatric Palliative Care: Global Perspectives.** Netherlands: Springer.
19. Knapp, C. & Thompson, L. (2011). **Factors Associated with Perceived Barriers to Pediatric Palliative Care: A Survey of Pediatricians in Florida and California.** *Palliative Medicine*, p. 268–274.
20. Lindgren, D. (2015). **How to Make KAP* Surveys Work? (*Knowledge, Attitude, and Practice).** Retrieved from: <http://www.rapid-asia.com/rapid-asia-on-the-go/how-to-make-kap-surveys-work-knowledge-attitude-and-practice/> [Accessed 25 12 2016].
21. Miccinesi, G. et al. (2005). **Physicians' attitudes towards end-of-life decisions: a comparison between seven countries.** *Social Science & Medicine*, p. 1961–1974.
22. National Association of Pediatric Nurse Practitioners, (2017). **Pediatric Health Care/Medical Home.** Retrieved on May 12, 2017 from <https://www.napnap.org/pediatric-health-caremedical-home>
23. Nichter, M. (2008). *Global health: Why cultural perceptions, social representations, and biopolitics matter.* Tuscon: University of Arizona Press.
24. Paneduro, D. et al., 2014. **Development, Implementation and Evaluation of A Pain Management and Palliative Care Educational Seminar for Medical Students.** *Pain Research and Management*, pp. 230-234.
25. Pesut, B. et al. (2013). Program Assessment Framework for a Rural Palliative Supportive Service. *Palliative Care: Research and Treatment*, pp. 7-17.
26. Prem, V. et al. (2012). **Study of Nurses' Knowledge about Palliative Care: A Quantitative Cross-sectional Survey.** *Indian Journal of Palliative Care*, pp. 122-127.
27. Razban, F., Tirgaril, B. & Iranmanesh, S. (2015). **Nurses' knowledge about and attitude towards palliative care in Southeast Iran.** *Asian Journal of Nursing Education and Research*, pp. 399-404.

28. Ross, M. M., McDonald, B., & McGunness, J. (1996). The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursing*, 1996,23,126-137
29. S.El-Nagar & Lawend, J.(2013). **Impact of Palliative Care Education on Nurses' Knowledge, Attitude and Experience Regarding Care of Chronically Ill Children.** *Journal of Natural Sciences Research*, 3(11), pp. 94-103.
30. Shawawra, M. & Khleif, A. (2011). **Palliative Care Situation in Palestinian Authority.** *Journal of Pediatric Hematology/ Oncology*, pp. S64-S67.
31. Small, N. (2001). Social Work and Palliative Care. *British Journal of Social Work*, Volume 31, pp. 961-971.
32. SPRING & USAID (2011). *The KAP Survey Model (Knowledge, Attitudes, and Practices)*. Retrieved from: <https://www.spring-nutrition.org/publications/tool-summaries/kap-surveymodel-knowledge-attitudes-and-practices> [Accessed 24 12 2016].
33. Twamley, K. et al. (2013). **Underlying barriers to referral to pediatric palliative care services: Knowledge and attitudes of health care professionals in a pediatric tertiary care center in the United Kingdom.** *Journal of Child Health Care*, 18(1), pp. 19-30.
34. Unite for Sight (2015). *Unite for Sight*. Retrieved from: <http://www.uniteforsight.org/global-health-university/survey-methodologies> [Accessed 25 12 2016].
35. WHO, (2004). *the Solid Facts: Palliative Care*. s.l.: World Health Organization (WHO).
36. WHO, (2015). *Palliative Care*. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs402/en/>
37. WHO, (2016). *Definition of Palliative Care*. Retrieved from: <http://www.who.int/cancer/palliative/definition/en/>
38. Wiener, L., Mcconnell, D. G., Latella, L. & Ludi, E., 2012. **Cultural and Religious Considerations in Pediatric Palliative Care.** *Palliative and Supportive Care*, p. 47–67.
39. WPCA, W. P. C. A. (2014). *Global Atlas of Palliative Care at End of Life*, s.l.: WHO.
40. Yambo, M. (2016). **KAP as a Model of Behavior Change and Innovative Practice {CSO 589}**. Retrieved from at: <http://mauriyambo.blogspot.com/2016/03/kap-as-model-of-behavior-changeand.html> [Accessed 24 12 2016].
41. Zeinah, G. F. A., Al-Kindi, S. G. & Hassan, A. A.(2012). Middle East Experience in Palliative Care. *American Journal of Hospice & Palliative Medicine*, pp. 94-99.

Appendices

Appendix 1: Survey



Dear Participating Healthcare Professionals,

You are invited to participate in our graduation project survey. In this survey, healthcare professionals at Caritas Baby Hospital will be asked to complete a questionnaire that asks questions about an internationally emerging field which is Pediatric Palliative Care. The aim of this survey is to understand your thoughts and ideas about this field. Kindly note that completion of this survey will take approximately 15-20 minutes.

Your participation in this study is completely voluntary. However, if you feel uncomfortable answering any questions, you can withdraw from the survey at any point. It is very important for us to learn your opinions. In addition, please note that your survey responses will be strictly confidential and data from this survey will only be used for the research purposes.

Your information will be coded and will remain confidential. If you have questions at any time about the survey or the procedures, you may contact Mrs. Wafa Musleh.

Thank you very much for your time and support.

Part One: Participants Information Background

Please put circle around the correct answer:

- What is your gender?
 1. Male
 2. Female
- Your age in complete years: _____ years
- Please click your highest education?
 1. None
 2. Tawjihi (High School)
 3. Diploma
 4. Bachelor
 5. Master degree and more

- What is your current profession?
 1. Physician
 2. Nurse
 3. Social Worker
 4. Laboratory Technologist
 5. Radiologist
 6. Physiotherapist
 7. Pharmacist
 8. Administration Staff (Managers)
 9. Dietary Services Staff
- Years of experience at Caritas Baby Hospital: _____ years

Part Two: Please circle the answer that fits you best:

A) Knowledge Towards Palliative Care:			
#	Article	Answer	
		Yes	No
A1	Do you know the definition palliative care?	1	2
A2	Palliative care is only appropriate in situations of a downhill trajectory or deterioration in conditions.	1	2
A3	The extent of the disease determines the method of pain treatment.	1	2
A4	Adjuvant therapies are important in managing pain.	1	2
A5	Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	1	2
A6	The provisions of palliative care require emotional detachment.	1	2
A7	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	1	2
A8	The philosophy of palliative care is compatible with that of aggressive treatment.	1	2
A9	The use of placebos is appropriate in the treatment of some types of pain.	1	2
A10	Opioid (Morphine) is not an effective analgesic for the control of chronic pain.	1	2
A11	The accumulation of losses renders burnout Inevitable for those who work in palliative care.	1	2
A12	Manifestations of chronic pain are different from those of acute pain.	1	2
A13	Terminally ill patients have the right to choose “Do not resuscitate” (DNR).	1	2
A14	Terminally ill patients should be encouraged to have hope against all odds.	1	2

B) Attitude towards palliative care (Please circle the answer that fits you best)						
#	Article	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
B1	Palliative care is given only for dying patient	1	2	3	4	5
B2	As a patient nears death; the health providers should withdraw from his/her involvement with	1	2	3	4	5

	the patient.					
B3	Giving palliative care to the chronically sick patient is a worthwhile learning experience	1	2	3	4	5
B4	It is beneficial for the chronically sick person to verbalize his/her feelings	1	2	3	4	5
B5	Family members who stay close to a dying person often interfere with a professionals' job with the patient.	1	2	3	4	5
B6	The length of time required to give palliative care to a dying person would frustrate me	1	2	3	4	5
B7	Families should be concerned about helping their dying member make the best of his/her remaining life	1	2	3	4	5
B8	Family should maintain as normal an environment as possible for their dying member.	1	2	3	4	5
B9	The health providers should not be the one to talk about death with the dying person	1	2	3	4	5
B10	The family should be involved in the physical care of the dying person.	1	2	3	4	5
B12	It is difficult to form a close relationship with the family of a dying member.	1	2	3	4	5
B13	There are times when death is welcomed by the dying person	1	2	3	4	5
B14	Palliative care for the patient's family should continue throughout the period of grief and bereavement.	1	2	3	4	5
B15	The dying person and his/her family should be the in-charge decision makers	1	2	3	4	5
B16	Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.	1	2	3	4	5
B17	Palliative care should extend to the family of the dying person.	1	2	3	4	5
B18	When a patient asks, "health provider, am I dying?" I think it is best to change the Subject to something cheerful.	1	2	3	4	5

B19	I am afraid to become friends with chronically sick and dying patients.	1	2	3	4	5
B20	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	1	2	3	4	5
B21	I would be uncomfortable talking about impending death with the dying Person.	1	2	3	4	5
B22	It is possible for health providers to help patients prepare for death.	1	2	3	4	5
B23	Death is not the worst thing that can happen to a person.	1	2	3	4	5
B24	I would feel like running away when the person actually died.	1	2	3	4	5
B25	I would not want to be assigned to care for a dying person	1	2	3	4	5

C) Please Continue the questionnaire by circling the correct answer that's suites you the best:	
C1.	Initiate palliative care discussion: (Multiple response): 1. During diagnosis 2. When the disease progress 3. At the end of life
C2.	Do you inform terminally ill patient about their diagnosis? 1. Yes 2. No 3. Depending on families wish 4. Inapplicable
C3.	Factors considered when dealing with terminally ill patient: (Multiple response) 1. Spiritual 2. Medical situation 3. Cultural 4. Psychological
C4.	Cultural assessment during patient care should include (Multiple response) 1. Truth telling and decision making 2. Preference regarding disclosure of information 3. Dietary preference 4. Language, family communication 5. Perspective on death, suffering & grieving
C5.	Addressing psychological: 1. Emotional support 2. Counseling the patient 3. Hiding the truth
C6.	Whom do you involve in decision making? (Multiple response) 1. Patient 2. Family 3. My own 4. The health professionals
C7.	Communication to the family of terminally ill patient depends on: (Multiple response)

	<ol style="list-style-type: none"> 1. Family's ability to assimilate 2. Their involvement in decision making 3. Your willingness to disclose information
C8.	How do you assess patient pain? (Multiple response) <ol style="list-style-type: none"> 1. Location 2. Grade with face 3. Intensity 4. Quality
C9.	Please indicate your degree of spirituality: <ol style="list-style-type: none"> 1. Very spiritual 2. Spiritual to some extent 3. Not spiritual

D) Commonly use medication in your practice for severe pain?

Appendix 2: Interview



Faculty of Arts Master in Community Social Work Interview Protocol

Study Summary:

CARTIS Baby Hospital (CBH) is one of the oldest hospice care unit and now a medical facility within the Middle East to provide advanced medical care to Palestinian Children. Based on the theory of change, and within the framework of KAP (Knowledge, Attitude, and Practice), this study will use a mixed methods to examine and assess knowledge, attitude and practice of pediatric palliative care within CBH. Palliative care is about improving the quality of life of terminally ill patients, by targeting and treating physical, psychological, and mental health of patients and their families.

The interview protocol:

The interview with the participants will start with the following steps:

- 1- Introduce who will conduct this study: Wafa Musleh, a completed graduation requirement for the degree of master in Community Social Work at the Bethlehem University, under the supervision of Dr Iman Abu Sa'da, an Associate Professor at the Department of Social Sciences.
- 2- Introduce the aim of this research: it seeks to examine and assess the knowledge, attitudes and practices of pediatric palliative care within CBH.

- 3- Explain to the participants why they have been chosen, a multidisciplinary team from CBH pediatric staff; doctors, nurses, social workers, administration members will be interviewed.
- 4- Explain what is required from the participants by clarifying that each interviewee will be asked a set of questions related to pediatric palliative care practices and knowledge and also they will be asked to explain how they perceive Palliative care and how it could be integrated into the hospital medical services. Participants will be informed that the interviews will be recorded by a digital recorder (confirm).
- 5- Explain to the participants that the data will be transcribed at a later stage after collecting it. After the final report of this study, the data will be put for a disposal.
- 6- Explain to the participants that the interview will not take more than 45 minutes.
- 7- Assure to the participants that they are not under any commitments, they can withdraw at any point he/she wishes, during, after or before the interview.
- 8- Explain to the participants that the data which will be taken will be kept in a password-protected laptop. It will be harshly confidential and only the researcher will have admission to it. A report of the study will be submitted for Bethlehem University to complete the requirements needed for a master degree in Community Social Work but individual participants will not be identifiable in the research.
- 9- Explain that further information can be sought from the interviewer after or before the interview take place.

Background information:

To begin, I'd like to get some basic information about you (such your age, education and occupation). The reason behind collecting this information is that I can show those who read my study report that I managed to obtain the views of a cross-section of people. Please note that this

information is for the purposes of scientific research only. The information that you give will never to be used to identify you in any way because this research is entirely confidential, thus, it does not require you to write your name or anything refers to you. However, if you don't want to answer some of these questions, please don't feel that you have to.

1. What is your gender?

- A. Male
- B. Female

2. How old are you?

____ Years

3. What is your highest education?

- A. None __
- B. Tawjihi (High School) __
- C. Diploma __
- D. Degree __
- E. Master degree and more __

4. What is your current profession?

5. The degree of spirituality:

- A. Very spiritual __
- B. Spiritual to some extent __
- C. Not spiritual__

The interview suggested questions:

- How would you describe the current availability of services for children facing life-threatening illnesses at CBH?
- How would you describe the current quality of services for children facing life-threatening illnesses at CBH?
- What do you think when you hear the words “palliative care”?
- Can you describe paediatric palliative care in your own words?

- To what extent do you think current medical care for children facing life-threatening illnesses meet the needs of patients and their families? And how?
- What are areas of medical care for children facing life-threatening illnesses that need improvement at CBH? (Ideas: Diagnosis, Treatment Plans, Treatment / Medication or Hospice care or anything else).
- How would you assess your own knowledge and skills in meeting the needs of children facing life-threatening illnesses?
- What do you think is needed to improve care at CBH for children facing life-threatening illnesses? (participants will mention PPC)
- Is there anything else you would like to add?

“The goal is to add life to the child's years, not simply years to the child's life” (AAP, 2000).

Thank you: end of interview