# Assessment of the Quality of End of Life Conditions and Care of Children Admitted to Oncology, Haematology Centre and Critical Illness in ICU Children Centre

# تقيم نوعية خدمات نهاية الحياة و رعاية ألأطفال الداخلين الى مراكز ألأورام السرطانية و امراض الدم وألأمراض الخطيرة في وحدة العناية المركزة للأطفال

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**الخلاصة**

**خلفية البحث**: ان غالبية الوفيات بين الأطفال في المستشفى تحدث في وحدة الأورام، و وحدة امراض الدم و وحدة العناية المركزة .كما وانه ليس هناك طريقة موثوقة و صحيحة لقياس نوعية خدمات نهاية الحياة في قسم العناية التلطيفية للأطفال، بالأضافة الى قلة وجود دراسات لأختبار نوعية خدمات نهاية الحياة في إقليم كوردستان في العراق .

**الهدف:**الهدف من الدراسة هو لتقييم ادراك الممرضة فيما يتعلق بنوعية الخدمات للأطفال الذين يحتضرون في مراكز الاورام السرطانية ووحدة العناية المركزة في السليمانية.

**المنهجية**:أجريت دراسة (وصفية مقطعية)وتم اشتراك ستون ممرضة (30) في قسم ألأمراض السرطانية و (30) في قسم العناية المركزة لهذه الدراسة بدأ جمع البيانات من 20 أيار-20 تموز2016 . ولتحقيق اهداف الدراسة تم استخدام تصميم مسحي و صورة معدلة و مثبتة من استبيان نوعية الموت والأحتضار وقد استخدمت أسئلة مفتوحة و لجمع نتائج البيانات الكمية والنوعية.

**النتائج** : إن غالبية المشاركات سجلت بأن الأطفال الذين توفوا من جراء السرطان كانوا يعانون بشدة من الألام والنزيف والكابة و كانوا مرعوبين من المستشفى أكثر من الأطفال الذين كانوا في قسم العناية المركزة. كما ان أفراد عوائل الأطفال الذين توفوا جراء السرطان يبقون فترات أطول مع هؤلاء الأطفال قبل ان يتوفوا أكثر من أفراد عوائل ألأطفال اللذين كانوا في قسم العناية المركزة .لقد عانت المرضات في المجموعتين من ثلاث عوائق فيما يتعلق بتقديم عناية نهاية الحياة مثل عدم توفر وحدات خاصة بالتلطيف مع عدم توفر عناية التلطيف القياسية في وحدتي الأمراض السرطانية و وحدة الأمراض الخطيرة وعوائق مؤسساتية وتنظيمية بالأضافة الى ان افراد العوائل الذين يبقون فترات طويلة مع مرضاهم ويهتمون برعايتهم يشكلون عائقا بالحد من دور الممرضة (العائق العائلي).

**الإستنتاج**: خلصت نتائج هذه الدراسة أن هناك بعض الاختلافات الهامة بين نوعية وفاة الطفل بين مرضى السرطانو غيره,أبلغ عن ثلاثة حواجز من قبل الممرضات التي قد تعيق وصول نهاية خدمات الحياة، مثل (مؤسسة و حاجز التنظيمي، حاجز الأسرة والدور المحدود لحاجز الممرضة.

**التوصيات**:إن العناية الأساسية بالمرضى المتدهورين ضرورية.كما ان التعليم المستمر للممرضة فيما يتعلق برعاية المرضى الذين هم على وشك الموت ،هو من الضروريات .

**Abstract:**

**Background:** The majority of deaths among hospitalized children happen in the Oncology, Haematology Unit and also in the ICU. There is no well-defined, reliable and valid method for measuring the quality of end-of-life care in the field of pediatric palliative care; further, limited studies that have examined the quality of dyeing experience among children in the Kurdistan Region of Iraq.

**The aim** of this study was to assess the nurse's perceptions regarding the quality of children dying experience in the Sulaimanea Oncology and ICU Centre.

**Methodology:**A cross- sectional descriptive studywas conducted and sixty nurses (30 Oncology and 30 ICU nurses) were recruited in the study.The data collection started from May 20th to July 20th 2016. Study objectives were addressed using a survey design; a modified validated Quality of Death and Dying questionnaire and open ended questions were used in order to collect the quantitative and qualitative data Findings:

**Results:**The majority of participants reported that cancer dying children were significantly suffered pain, bleeding, stress and terrified from the hospital more than ICU dying children and also cancer children, family seem to stay with their child during death time more than the ICU children families. Nurses in both settings faced three barriers in offering the end of life care, such as no palliative unit available along with no adequate palliative care offered to the patients as standard in both Oncology and critical care settings (Institution and organizational barrier). Further, the family also makes a barrier as they spent too much time with their children and participate in the care of their children (family barrier), and limited role of the nurses barrier.

**Conclusion:** The findings of the present study conclude that there are some significant differences between the quality of a child's death between Cancer and non- Cancer patients Three barriers were reported by the nurses that may hinder the access of end of life services, such as (Institution and organizational barrier, family barrier and limited role of the nurse's barrier)

**Recommendations:** Standard end of life care is necessary to manage deterioration patients and also a continuous specific end of life care education course are required for the nurse working in these settings.

**Keywords:End of life care, Palliative care, Cancer, Children, Critical illness, Intensive care unit.**

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## Introduction

Cancer is the second leading cause of death among children after the accident[1]. In 2014, out of 15,780 children and adolescents ages 0 to 19 years who were diagnosed with cancer, 1,960 of them died of the disease in the United States [2]. The most common Cancer type in children are acute lymphoblastic leukemia (ALL) (26%), followed by brain and central nervous system (CNS) tumors (21%), neuroblastoma (7%), and non-Hodgkin lymphoma (NHL) (6%) [3]. Much of the care of the dying is still provided by the nurses in the hospitals, primarily in oncology and critical care areas [3].In the last century, the majority of the dying settings took place in the hospital and institutional place rather than at home [4].Therefore, evaluation of the end of a lifetime is important for the nurses to prepare for the assessment of the circumstances of death [5].

In fact, to identify the quality of end of life care, the majority of researches has focused more increasingly on the perception of the patients, family and physician, however, the perception of nurses has received a minimal attention. Indeed, the nurses spend more time with each patient as a first hand instructor and create a healthy relationship with the family at this critical and emotional time [6,7].The most important thread of nursing care at the end of life is pain and symptom management, ethical decision making, competent, culturally sensitive care, and assistance through the death and dying process. Furthermore, effective communication skill and active listening to the patients and their family can improve the healthy relationship.

There is a lack of the well-defend reliable and valid methods to measure the quality of the end of child life care [8].Therefore, assessing the quality of dyeing experience in the period of deterioration, as perceived by the oncology nurses, is important in order to analyze the quality of care that is offered to the children. The quality of life for dying patient means the quality of death. The main goal of the pediatric palliative cancer care is to provide a concurrent therapeutic management; nurses pay greater attention to the delivery of physical, psychological, spiritual, educational, communication and end of life care, but they also have a vital role in cultural ethical consistent care in end of life time [9].It is extremely difficult to deal and communicate with children at the end of life as they are at an incredibly young age, the symptoms of this disease may have made them extremely weak and the fear of death may also have an effect on their mental health. The essential skills for successful relationships and effective communication are the openness and honesty of the nurses with their family at the end of life time [10].

In an academic children's hospital, 117 nurses and physicians were interviewed in a survey to describe the perceived barriers that they faced while caring children at the end of life time, fourteen barriers were estimated by >75% of the health professionals, such as uncertain prognosis (55%), family not ready to acknowledge incurable condition (51%), language barrier (47%) and time constraints (47%), along with communication barrier and also inadequate education about pain management and palliative care [6]. Consequently, caring for children at the critical condition is much harder than for the adult and elderly and active care and support for the child's body, mind, spirit and their family needto be available in Palliative care department [11].

The parents may be concerned about the quality of care that is offered to their children in the life limiting conditions, which may need improvement. Furthermore, they are also likely to be anxious about losing their child and thinking about the impact of the disease on their child as they had a poor lifestyle during the course of disease along with a complex treatment as a result of their advanced cancer [12] .The greatest quantity of the family reports that children with cancer developed a new dependency on others. Therefore, parents in these critical care settings are less likely satisfying to the care than the other hospital, they often experience the poor quality of communication between them and health care provider and also a financial and emotional burden as a result of their child's condition [13].Hence, the family should be involved in the process of planning care decisions as children need to "talk with them not talk about them". Therefore, telling truth about their condition can cause pain to the children.

According to the literature, almost all of the nurses reported that care of the dying patients leads them to feel frustrated, especially in the acute hospital ward. Seven board domains need to be identified in order to determine the quality of death from the perspective of the deceased's family along with professional caregivers, which includes: physical, psychological, social, spiritual or existential domains; the nature of health care; life closure and death preparation; and, the circumstances of death [14].Therefore, children at the end of life time received a symptom management to support their life.

The Committee of End of Life Care of the Institute of Medicine, define quality of dying experience as any death that free from patient, family and care giver's distress and concern, also the care should be consistent clinically, culturally and ethically. There are two types of dying experiences which are "good death and bad death". The main themes that may contribute the concept of the good death is when some of the physical, psychological, social and spiritual distress symptoms of the patients and their family has felt in control, for example, 46.8% of patients are suffering from pain, also dyspnoea, spiritual and emotional symptoms still appear as a symptom of stress at the end of their lifetime, which may affect the quality of death [15,16]. Regular training is important for all critical care nurses and oncology nurses who are involved in caring for dying persons to support the bereaved families psychologically, to give a standard care in practices and train on making an effective relationship at the end of life As a consequent, improving the education of the nurse regarding pediatric end of life care can lead to a development of the pediatric palliative care.

## Objectives:

The aim of this study is to assess nurses' perceptions and barriers in providing quality of end- of-life care for dying children, this aim will be addressed through the following objectives:

**1.** To assess the perception of the nurse regarding management of deteriorating children.

**2.** To examine the nurse's barrier of care through an end of life care.

**3.** To examine the nurse's plan of care through an end of life care.

**4.**To compare the quality of dyeing experience between Oncology cancer and ICU critical patients.

## Methodology:

A cross- sectional descriptive study was used in this study. A mixed methods study involves the collection or analysis of both quantitative and qualitative data in a single study in which data are collected can currently or sequences are given a priority, and involve the integration of the data at one or more stage in the process of research

[17]. The official permission was obtained from the local authority in the hospital after the explanation of the aim of the study and subsequently a questionnaire was made by the researcher in order to gather the demographic information of the nurses. The Quality of Death and Dying (QODD) questionnaire was modified and translated to the Kurdish language by the researcher and it was reviewed by a few professional translators to validate the quality of the translation. The tools that were used in this study were proven to be validated by 4 experts in the field. An explanation was given to the nurses in order to gain their consent.

## Setting

This study was carried out in the Oncology, Haematology at Hew Hospital and ICU Centre at Sulaimania Pediatric hospital in Kurdistan Region of Iraq. These settings were selected as many of the children dies in these centers.

## Procedure

The researcher met the clinical manager of the both units in order to publicize the study. Then the researcher arranged the appointments with each the Oncology-Hematolgy and critical care nurses. The individual data collection for respondents started from May 20th to July 20th, 2016 and took place at the Oncology and Children Intensive Care Units, respectively, and was undertaken using a well prepared and translated questionnaire. The researcher was on hand to assist with any clarifications if needed.

Participants completed a brief biographical questionnaire (work experience, age, gender, experience of work, job title and place of work). Then, a set of 22 direct questions was displayed on the site about an instance of a child physical, psychological and spiritual complain of cancer and critical diseases. Then, participants were asked to make a judgment by responding to three open ended questions. The survey lasted about 20 min and participants were thanked for their participation and debriefed before they left the room.

## Sampling

Probability sampling was used in this study, all the Oncology and ICU Nurses were recruited in the hospital after their signed consent to participate in the study (total number=60, out of which 30 were Oncology nurses and 30 were Critical care nurses). An individual self- report structured interview was conducted with each nurse working in oncology and ICU children's ward, as all of them working in Hewa Hospital in the same place to manage children with oncology and critical diseases in ICU.

## The questionaire

In order to gather data for the current study, first asks about the demographic data such as: age, gender, level of education, occupation, length of time working in the center, professional background. Followed by the questions that will be about the conditions of children at the end stage and also the amount of services that the dying person has been given in the hospital, for instance, did the patients receive enough help with the pain, dyspnoea and emotional support. Furthermore, asking about the family perceptions and concerns about the appropriate care has been given to their dying person in the last few days of dying.

Various adjustments were made to the validated tool (QODD) which was developed by Ptrick et al.[18].After a great amount of effort on finding a relative questionnaire for assessing the quality of dying and death experience among children, unfortunately, there was not a specific tool available for this specific age group. The questionnaire was modified so that the questions were age appropriate and validated by 4 experts, two academic professors from University of Plymouth in England and two Oncologists at

Hewa Hospital in Sulaimania City. In addition, this questionnaire was piloted by a small number of nurses (n=4) to improve clarity.

The modified questionnaire consists of 24 questions, the first 22 was direct questions which asked in order to determine the children's condition in deterioration time and Q22 was two parts, first direct question and secondly asking more about the types of end of life services if available then the other two questions (23,24) were an open ended questions asking their barriers in acting their role as a nurse to offer the suitable end of life care to those children admitted to both settings and finally the researcher were asked the nurses about their plan for the future and also their suggestions to provide the significant quality of care to support these patients at the end- stage. This tool was translated to the Kurdish language to facilitate understanding in the process of the interviewing.

## Quantitative data analysis

Descriptive analyses were achieved calculated the demographic data. The Mann-Whitney U Test was used to show the significant differences between the two groups (ICU & ONCOLOGY) depending on the nurses' perception, if the p value is less than 0.05.

Further, to compare between the two groups (ICU & ONCOLOGY) generally not for each question in this case, this study has depended on (Median) as a central tendency measurement for each question and for the two groups, found (22) median for ICU group and (22) median for the second group ONCOLGY (that means each question has one median). All the statistical analysis was conducted with the help of the statistical package for social sciences software (IBM SPSS statistics), version 21.00.

## Open ended questions analysis

Responses to the open ended questions were analyzed using thematic analysis. Framework analysis is particularly useful for applying our policy-related qualitative data in this study the policies being examined relate to the barriers that Oncology and ICU nurses were faced when they deal with those children at the end of lifetime. Further, analyze the perception of the nurses regarding their suggestions and plan for making better palliative care in the future [19].

# Results:

## Characteristics of respondent

**Table (1)** distribution of respondent demographic data items

| Variables | Demographic data | Oncology Nurses (n=30) | | ICU Nurses (n=30) | | TOTAL (n=60) | |
|---|---|---|---|---|---|---|---|
| | | F | % | F | % | F | % |
| **Age** | 20-25 years | 11 | 36.6% | 4 | 13,3% | 15 | 25% |
| | 26-30 years | 10 | 33.4% | 2 | 6.6% | 12 | 20% |
| | >30 | 9 | 30% | 24 | 80% | 33 | 55% |
| | Total | 30 | 100% | 30 | 100% | 60 | 100% |
| **Gender** | Female | 7 | 23.3% | 4 | 13.4% | 11 | 18.4% |
| | Male | 23 | 76.7% | 26 | 86.6% | 49 | 81.6% |
| | Total | 30 | 100% | 30 | 100% | 60 | 100% |
| **Job title** | College nurse | 4 | 13.4% | 9 | 30% | 13 | 21.6% |
| | Institute Nurse | 22 | 73.4% | 7 | 23.4% | 29 | 48.4% |
| | Ungraduated | 1 | 3.3% | 14 | 46.6% | 15 | 25% |
| | Psychologist | 2 | 6.6% | - | - | 2 | 3.4% |
| | Social worker | 1 | 3.3% | - | - | 1 | 1.6% |
| | Educator | - | - | - | - | - | - |
| | Total | 30 | 100% | 30 | 100% | 60 | 100% |
| **Length of time working in the hospital** | <2 years | 8 | 26.7% | 3 | 10% | 11 | 18.4% |
| | 2-5 years | 18 | 60% | 5 | 16.6% | 23 | 38.3% |
| | 6-10 years | 4 | 13.3% | 6 | 20% | 10 | 16.6% |
| | >10 years | - | - | 16 | 53.4% | 16 | 26.6% |
| | Total | 30 | 100% | 30 | 100% | 60 | 100% |
| **Place of work** | Oncology | 30 | 50% | - | - | 30 | 50% |
| | ICU | - | - | 30 | 50% | 30 | 50% |
| | Total | 30 | 100% | 30 | 100% | 60 | 100% |

**Table 1** shows that the majority of the oncology nurses were aged between (20-30 years). However, ICU nurses were older, mostly 24 (80%) aged (>30 years). Across the whole sample, most (49, 81.6%) of the nurses were male. Further, (16, 53.4%) of the ICU Nurse respondents had worked at the hospital for over 10 years rather than Oncology nurses. 22 (73.4%) of nurses working in Oncology were instituted nurses (Graduated nurse with Institute Diploma); however, the institute nurses that work in the ICU were less than this number 7 (23.4%), with 9 (30%) college nurses (graduated nurse with BSC degree) and 14 (46.6%) ungraduated nurses (no degree nurses), with no psychologist and social worker available in ICU. In contrast, 2 (6.6%) psychologists and 1 (3.3%) social worker were worked in the Oncology Center.

## Nurses perception (quantitative findings)

**Table (2)**Oncology and ICU nurses' perceptions regarding children's end of life conditions.

| No. | Questions | Oncology Nurses | | | ICU nurses | | |
|---|---|---|---|---|---|---|---|
| | | Yes | No | Uncertain | Yes | No | Uncertain |
| 1 | Did the patient suffer from the disease pain? | 83% | 17% | 0% | 57% | 43% | 0% |
| 2 | Was patient breathing comfortably like (SOB)? | 56% | 37% | 7% | 13% | 80% | 7% |
| 3 | Did the patient suffer from nausea or vomiting? | 60% | 37% | 3% | 53% | 43% | 10% |
| 4 | Did the patient suffer from convulsion? | 73% | 25% | 3% | 70% | 23% | 7% |
| 5 | Did the patient suffer from bleeding? | 83% | 13% | 3% | 57% | 30% | 3% |
| 6 | Was the patient able to feed him/herself? | 7% | 90% | 3% | 10% | 83% | 7% |
| 7 | Did the patient feel depress or anxious? | 73% | 25% | 10% | 47% | 50% | 3% |
| 8 | Was patient happy in relation with medical staff? | 57% | 40% | 10% | 50% | 40% | 10% |
| 9 | Did the patient compliance with the treatment | 67% | 30% | 7% | 67% | 33% | 0% |
| 10 | Was the patient mood from hospitalization? | 87% | 7% | 3% | 60% | 37% | 3% |
| 11 | Were patient's family members aware that he or she was dying? | 57% | 7% | 0% | 97% | 3% | 0% |
| 12 | Did the patient spend enough time with his or her family during dying? | 93% | 30% | 3% | 87% | 13% | 0% |
| 13 | Was there a member of his/her family during dying? | 37% | 7% | 3% | 73% | 27% | 0% |
| 14 | Was patient given a chance to express his or her feelings? | 53% | 40% | 3% | 67% | 30% | 3% |
| 15 | Did the patient receive visits from religious advisor? | 30% | 47% | 7% | 43% | 50% | 7% |
| 16 | Did The patient have specific wishes that cannot be achieved in his/ her life? | 7% | 63% | 7% | 33% | 67% | 0% |
| 17 | Was the child still able to engage in play? | 24% | 7% | 0% | 17% | 83% | 0% |
| 18 | Was child able to be comforted by family members? | 80% | 20% | 0% | 63% | 37% | 0% |
| 19 | Was the child still able to respond to family members? | 50% | 50% | 0% | 53% | 37% | 3% |
| 20 | Did the child seem to be afraid? | 67% | 30% | 3% | 37% | 53% | 3% |
| 21 | Are any (Palliative Unit) available in the children's unit | 33% | 67% | 0% | 0% | 100 % | 0% |
| 22 | Is there any end of life care (palliative care) available at your Centre? | 33% | 67% | 0% | 16% | 84% | 0% |

**Tables 2** illustrate the quality of death and dying experienced by both cancer and non- cancer children at the end stage, depending on the self-report of the nurses in both (Oncology and ICU settings). The findings show that children in the oncology unit were more likely than those in ICU to: suffer from pain (83% vs. 57%) have breathing difficulties (87% vs. 80%), suffer from nausea and vomiting (60% vs. 53%) and suffer from bleeding (Question 5) (83% vs. 57%). In both places patients who were in end of lifetime suffered from convulsions. The majority of the patients in both locations is dependable in terms of feeding, and self-care. Cancer patients in oncology were more depressed and anxious, whereas, in ICU the majority did not feel this way.

**Table (3)**Summary of outcome Mann-Whitney U analysis with significant variables (Oncology and ICU Nurses) for each question.

| Q# | Question | Mann-Whitney U Test | Sig. (2-tailed) | Decision |
|---|---|---|---|---|
| 1 | Did the patient suffer from the disease pain? | 330.00 | 0.025 | S |
| 2 | Was the patient breathing comfortably like (SOB)? | 449.00 | 0.982 | NS |
| 3 | Did the patient suffer from nausea or vomiting? | 401.50 | 0.422 | NS |
| 4 | Did the patient suffer from convulsion? | 431.50 | 0.728 | NS |
| 5 | Did the patient suffer from bleeding? | 309.50 | 0.011 | S |
| 6 | Was the patient able to feed him/herself? | 449.50 | 0.99 | NS |
| 7 | Did the patient feel depress or anxious? | 334.00 | 0.045 | S |
| 8 | Was the patient happy in relation with the medical staff? | 393.50 | 0.347 | NS |
| 9 | Did the patient compliance with the treatment | 405.00 | 0.431 | NS |
| 10 | Was the patient mood from hospitalization? | 360.50 | 0.093 | NS |
| 11 | Were the patient's family members aware that he or she was dying? | 404.00 | 0.156 | NS |
| 12 | Did the patient spend enough time with his or her family during dying? | 358.00 | 0.064 | NS |
| 13 | Was there a member of his/her family during dying? | 360.00 | 0.039 | S |
| 14 | Was the patient given a chance to express his or her feelings? | 421.00 | 0.611 | NS |
| 15 | Did the patient receive visits from religious advisor? | 391.00 | 0.322 | NS |
| 16 | Did The patient have specific wishes that cannot be achieved in his/her life? | 439.00 | 0.853 | NS |
| 17 | Was the child still able to engage in play? | 380.00 | 0.095 | NS |
| 18 | Was the child able to be comforted by family members? | 375.00 | 0.155 | NS |
| 19 | Was the child still able to respond to family members? | 442.50 | 0.90 | NS |
| 20 | Did the child seem to be afraid? | 309.50 | 0.019 | S |
| 21 | Are any (Palliative Unit) available in the children's unit | 450.00 | 1.00a | NS |
| 22 | Is there any end of life care (palliative care) available at your Centre? | 350.00 | 0.08 | NS |

**S: significant; NS: Non significant**

**Tables 3**compare all the questions that were answered by the nurses. There are some significant differences in the answer of nurses to the question (1, 5, 7, 13 and 20) at $p<0.5$, which are p value=0.025, 0.011, 0.045, 0.039 and 0.019, respectively, this means that oncology children at the end of life were suffering pain, bleeding and stress more than those in ICU, and also the significant differences were indicated in the interaction of children with their family members during the bereavement time, as found that family of cancer children seem to stay with their children more than the ICU children's family, this gave them the chance for family members to witness their patient's death especially in oncology. Children in oncology were terrified from the hospital rather than in the ICU. However, the significant differences were not found between two groups of nurses for the other seventeen questions. According to the result of Mann-Whitney U Test,

**Table (4)**Mann-Whitney U analysis (p-value) generally between the oncology nurse's and ICU nurse's perception.

| Nurse's Perception | N | Mean Rank | Sum of Ranks |
|---|---|---|---|
| ICU Nurse | 22 | 24.77 | 545.00 |
| Oncology Nurse | 22 | 20.23 | 445.00 |
| Total | 44 | | |

| Statistics | Nurses perceptions |
|---|---|
| Mann-Whitney U | 192.000 |
| Wilcoxon W | 445.000 |
| Z | -1.348- |
| Asymp. Sig. (2-tailed) | .178 |

With regard to the general differences in the perception of Nurses for the whole questions, **Table 4**shows that there are no significant differences between the views of nurses in both settings. According to the Mann-Whitney U Test value equal (192.00) and significance value equal (0.178), it is more than (0.05) that means that the study accept Ho and reject (can't accept) H1, That means there are no significant differences in median between the groups (**Table 4**).

## Qualitative findings

**Table (5)** The perceptions (qualitative findings) of the oncology and critical care nurses.

| OncologyNurse's Perceptions | CriticalcareNurse's Perceptions | Themes |
|---|---|---|
| Doesanything make it difficult to manage this child at the end of life stage? And What is your plan to improve end of life care? | | |
| **Issue:** We are not isolating the patients as standard it is just giving supportive treatment, monitoring them by a college nurse **Plan**: Isolated area should be available to decrease the crowded from the area, especially during the end of life **Issue:** The place of the hospital should be far from living people place as our hospital is in the middle of people living **Plan:** Transfer the hospital in the broader area and far from a living people place **Issue:** Too many patients with too lack bed **Plan:** Admit the patients depending on theavailabilityofbeds **Issue:** No palliative unit and material for those patients **Plan:** Blood bank is important to be there and also platelet should be available **Issue:** Too narrow space between the patient's bed and others which make barriers to our services, especially in end of lifetime **Issue:** No developed instrument for intensive care **Issue:** No, we are not isolated as | **Issue:** There is not a suitable place to treat these children in this stage as this child is beside the other patients with hope for life **Plan:** Children were needed to put in the isolated area in order to deal with them at this stage **Issue:** Yes, our ICU is very small and the crowd and the beds are too close and do not allow us to do what we do for our patients **Issue:** No isolated place which is far from the family during this sensitive and painful time and also There is no emergency box or tray **Plan:** The regular rule to admit the patients also concerned about the huge number of patients admitted to the small place with a limited beds **Issue:** No special doctor available at this sensitive time **Plan:** as the doctor should be there in time when the baby close to end of life in order to explain the condition to the child's family **Issue:** No psychologist available in this area as there is no standard intensive care and also No Social worker available **Plan:** Psychologist and social workers should be available there to support the patients, families and health professionals | **Institution And Organizational barriers & Plan to solve** |

| | | |
|---|---|---|
| standard it is just giving supportive treatment, monitoring them by a college nurse **Plan:** Isolate the patients depending on their cancer | **Issue:** No pain assessment unit **Plan:** to assess the child's pain associated with the disease, this unit is important to have **Issue:** The services in our country are just giving drug as there is no any explanation of the procedure to the patients and their family because of that the patient's family make a barrier | |
| **Issue:** The barrier from the patient's family as they are not trusting our services, and they are hopeless about their child's life and they blame about the quality of services that affects their skill **Plan:** we should make a therapeutic relationship with them and be a good listener to their complaints **Issue:** Patient's family bothering us, as they | **Issue:** Patient's family, which they are not accepting their child's end of life, so they used a not preferable behavior **Plan:** these families need to participate them in some related educational program **Issue:** Patient's family, as they are very upset about their child's condition **Issue:** No psychological support available to the patients and their family during deterioration time, | **Family barrier** |
| **Issue**: The doctors sometimes not letting us participate in the management of patients in end of life stage **Plan**: Taking into account the perception of nurses during the treatment | Issue: Lack of Cooperation between nurses and patients and also between nurses and doctors Plan: Teamwork is the best solution to get the services better, and the team should introduce theirself to the patients | |
| **Plan**: make teamwork staffs which is contained (social worker, psychiatrist, religion person, professional nurse **Plan**: Psychologist should be available for us to support us working comfortably Issue: Not applying the infection control **Plan**: follow up of the infection control team to our unite us learning is not enough we need to apply that **Issue**: No training to learn how we can deal with these patients Issue: No training for nurses about cancer Plan: Training for staff in order to educate them with the standard information | Issue: our job is Continuous monitoring of the child, Administrating all the prescribed drug,There is no that opportunity to document our work, so Recording and documentation of all the child's conditions Plan: if there is a team work there is a plan if there is a plan, there is a good service with good outcome Plan: Increase the number of nurses and educate the nurses by participating them in the special end of life care training Issue: lack of the our education about the pediatric end of life care Plan: Educate the nurses by participating them in the special end of life care training | **The limited role of nurses barrier & Plan to solve** |

In addition to the responses to the 22 multiple choice questions, the respondents were asked an open question: Does anything make it difficult to manage this child at the end of life stage? If the response was answered yes, which was given by 98% of respondents, they were also asked to provide deep and broad information about the future plan on how you can make these services better? As a consequence, thematic analysis was used to analyze all lexical items, sentences, and paragraphs in order to extract themes regarding the barriers that respondents face. According to the open

ended question, when the researcher asked about the availability of the palliative unit, all (100%) of nurses was answered no.

However, with the question about the availability of palliative care, these views weren't shared by all nurses only 30% of nurse's answered yes. While, 27% ICU nurses were experienced differently and stated that they have offered the palliative care. The nurses were answering a question; hence the excerpts often start with a unavailability of palliative unite as a factor. In terms of the technique of the palliative care, 30% of Oncology nurses raised an issue regarding the (Palliative care). Three themes were derived from the raw data such as (institution and organizational barriers, family barriers and the limited role of nurse's barriers), so there was not a pre-determined theme. The barriers and plan to alleviate them are reported according to the Nurses perception is shown in **Table 5.**

## Discussion

Recent research is the first that revealed the nurse's perceptions regarding the significant problems in the care of dying children and their families in this region. Therefore, the participants described their experiences of their ability to cope with a child's death. Further, palliative care also is important to have in order to achieve goals of end of life care to children with cancer and critical illness [19]. Finding in this study indicates that in this country these services are closely linked as an integrated care to oncology departments. This confirms the findings of the previous study [20], estimated that palliative care in most of the country is linked to Oncology department.

Patric and colleagues mentioned that the high quality of death has meant the death that free of discomfort and full of wishes [18].The primary indicator of the quality of end of life care is the ability of the nurses to manage the physical and psychological discomfort of the patients such as pain and dyspnea and also controlling the stress feeling of the bereaved family [21]. Depending on the nurse's perception, the current study demonstrates that for those children who have cancer is more likely to suffer from pain (83%) rather than those who admitted to ICU (57%). This is strongly agreed by a cross sectional study of Gameel and Kandeel [22], who interviewed 45 oncology nurses, they were reported that a cancer patients were more likely suffered from pain rather than those who died in the ICU. This was also a finding of the retrospective cohort study done by who interviewed parent's proportion and reported less child suffering from pain and dyspnea at the end stage in the ICU [23].

These findings are also relevant to the clinical experience of who reported that pain was documented as one-third to onehalf of cancer patients as a result of illness, its treatment, or co-occurring illnesses [24].Our study found, that the patients in oncology are more likely suffered from nausea and vomiting than those in ICU. As supported this finding and stated that nausea and vomiting in the person with cancer are commonly caused by cancer itself and also as a side effect of chemotherapy and radiation therapy. However, in both places patients who were in end of lifetime suffered from convulsions [25]. Bleeding is more likely experienced by Cancer children. In addition, patients in oncology are more terrified of hospitals than those in the ICU and this can be related back to the fact that their treatments are not the same. In both centers, family members are aware of their patient's status. Further, in this study, patients in both centers complained of the treatment as they were at the end of life time. In the current study, nurses also confirmed that the level of detail in the expression of feelings varies depending on the child's age and the level of maturity. Therefore, the older they are more expressing their wishes than smaller in age, this reflects what pointed out that it is

difficult for the children to understand the concept of death, especially before the school age. In addition to the age, this study reported the importance of illness in understanding the meaning of death [26]. As the nurses in the current study indicated that for those in ICU have expressed feeling at range 67% rather than those who were in Oncology, majority of children in both centers were unable to engage in play time. The recent study has revealed a significant barrier in the care of the children at the end stage.

With Regard to the unavailability of the palliative unite, the majority of nurses were concerned about the settings, as all the patients "hopefulness and hopelessness children in the life" were mixed in the same place. Therefore, this might raise the family awareness about their child's condition and also cause frustration to the children, which they might need psychological support. Therefore, most of them might need supportive treatment in terms of having pain, dyspnoea, bleeding and convulsion. Unlikely, the majority of nurses in the current study mentioned that there is no special pain management unit available in the both critical care settings. In the case presentation study stated that it is important to control pain among children with life-threatening conditions, which can lead to improve the quality of life [27,28]. Defined palliative care as a multidisciplinary approach to implement an active management to the children physically, psychologically, socially and spiritually and also support the family before and after their child's death. Further, mentioned that the important aim of palliative care is to emphasis on the quality of life of the patients and their families rather than the quantity of days lived [29]. This service should be available in an isolated palliative unit, as these studies are in contrast to the current study finding, as majority of nurses were mentioned that children with the life threatening disease at the end stage were not isolated as standard.

In addition, according to the policy of the hospital in this country all the visitors were allowed to visit the patients at the end stage, which this might lead to making the area noisy and crowded. According to the nurse's perception, family were allowed to spend a huge amount of time with their children. This gave them the chance for family members to witness their patient's death especially in oncology. The majority of the nurses in both settings were concerned about the behavior of the family as they felt pain because of their child's condition and they are not well prepared for this situation. In contrast to the retrospective cohort study, which made a survey with 119 parents and also data from a review chart, recorded that 29% of the family are "very prepared" to the medical problem of their children at the end of stage As, Davies et al[6]indicated that when the family are unprepared for their child's situation, this can lead them to provide unrealistic expectations about the future of their children.

In addition to that, the participants outlined some other issues regarding the family participation in their child's care, stated that family were impacted them to practice their role as a nurse to offer the needed health services to their children at the end stage, as they make a noise in the area and also it affect the process of infection control. In contrast to the Bloomer study, who reported that the nurses were happy to the parents to involve in their children's end of life care. As this highlighted by some other previous studies, which also discovered the importance of parent participation in the decision of care management. Despite the interactive time that the nurses spent with the family, however, they acknowledged that they fell frustration and discomfort[29]. This finding is confirmed by the finding of the focus group interview with 19 nurses who provides care to the family before and after child death, they reported that as a result of

the aggressive continuing of the treatment they suffered from discomfort and frustration [30]. Therefore, as suggested by most of the Nurses that psychologist is required to support their discomfort, as it is right for them.

The standard rule for the palliative care should be working as a team The team may consist of doctors, nurses and allied health workers such as social workers, psychologists and therapists as well as religious, philosophical or bioethical professionals [25,31]. Arguably, these facts are in contrast with the current study finding, as nurses indicated that there is no team work with their limited role as a nurse and also ICU nurses were concerned about the unavailability of the special physician working 24 h in this area. Further, they were complaining about the unavailability of the psychologist to support the patients and their family emotionally. As this was also raised the awareness of some pediatric providers, who participated in a study conducted in an academic hospital noted time constraints (47.2%) and staff shortage (31%), which always may impact on providing good end-of-life care[32]. The limited role of the nurses in these settings was one of the other barriers of the nurses as they were not involved in the decision and not taking into account their decision in terms of the care plan. In contrast to the finding of reported that nurses have an integral role in implementing the PPC (Paediatric Palliative Care) in order to decrease the suffering of the children with cancer and their families. Furthermore, nurses are also requested the continuous training course in terms of managing these children at the end stage, in addition to the specify of these critical areas, the majority of nurses were acknowledged to not mix them with the other area nurses in the training. In the qualitative- semi structure interview study done in Kurdistan Region, supported this finding and suggested the importance of the continuous training course for the nurses in Kurdistan region of Iraq.

This study may confirm significant in contributing to an area, which is currently under researched in this Region and will generate further studies in this field [33]. However, some limitations have addressed, in terms of the study method, exploratory interview like focus group might be more significant than a structured interview to share and discuss information and gain a richer findings [34]. In addition, the perception might reflect the reality of death if the family and child's perception was also undertaken instead of just taking the nurses perception, as a consequence a better subjective experience can be achieved along with an additional insight to the aim of the study. The further observational study will suggest by the researcher and also incorporate the pediatric palliative care to the curriculum of the school of nursing as a subject to prepare the student nurses and also to improve their knowledge and skill[35].

## Conclusion

The findings of the present study conclude that there are some differences between the quality of a child's death between Cancer and non- Cancer patients. Further, this study reveals the limited end of life services in both settings. Three barriers were reported by the nurses that may hinder the access of end of life services, such as (Institution and organizational barrier, family barrier and limited role of the nurse's barrier). The unavailability of the standard institution (palliative Unit) for the good death of children is posed as a major challenge to the patients first then to the family and health professionals. Along with the family barriers as they impacted on the end of life services and also the limited role of the nurses in making the decision as a system barrier.

## Recommendation

1. Some suggestion plan was addressed to solve these barriers in order to improve the end of life care in both oncology and ICU settings.
2. Standard end of life care is necessary to manage deterioration patients and also a continuous specific end of life care education course is required for the nurse working in these settings.

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