

# **Evaluation of Nurses Performance of Standardized Palliative Care for Oncology Children**

*Thesis*

*Submitted For Partial Fulfillment of Requirement of  
Master Degree in Pediatric Nursing*

*By*

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# **Evaluation of Nurses Performance of Standardized Palliative Care for Oncology Children**

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## List of Abbreviations

<b>Abbreviation</b>	<b>Full- term</b>
<b>ACS</b>	American Cancer Society
<b>ANA</b>	American Nurses Association
<b>ASCO</b>	American Society of Clinical Oncology
<b>CNS</b>	Central Nervous System
<b>CPR</b>	Cardiopulmonary Resuscitation
<b>CSFs</b>	Colony-Stimulating Factors
<b>DNA</b>	Deoxyribo Nucleic Acid
<b>HPNA</b>	Hospice and Palliative Nurses Association
<b>NCI</b>	National Cancer Institute
<b>NCP</b>	National Consensus Project for Quality Palliative Care
<b>NHPCO</b>	National Hospice and Palliative Care Organization
<b>NSAID</b>	Non-Steroidal Anti-inflammatory Drug
<b>PC</b>	Palliative Care
<b>PNC</b>	Palliative Nursing Care
<b>PPC</b>	Pediatric Palliative Care
<b>PPS</b>	Palliative Performance Scale
<b>RUG-ADL</b>	Resource Utilization Groups - Activities of Daily Living
<b>SPC</b>	Standardized Palliative Care
<b>SPNC</b>	Standardized Palliative Nursing Care
<b>WHO</b>	World Health Organization



## Abstract

**Background:** Standardized Palliative Care (SPC) is an approach that improves the quality of life of pediatric patients and their families facing problems associated with life-threatening illness. **Aim of the Study:** Evaluate nurses' performance of standardized palliative care for oncology children, through: Assessing knowledge, and practices of nurses regarding standardized palliative care for oncology children. **Research design:** Descriptive design was used for conducting this study; **a purposive sample** consisted of 65 nurses who are providing palliative care for oncology children and oncology children participate in the study. **Setting:** This study was conducted in the Out-patients and In-patients Pediatric Department at Children's Hospital affiliated to Ain Shams University and Department of Oncology Children at Menoufiya University Hospital. **Data collected** through using five tools including: I: Interview questionnaire sheet which consists of 2 parts: Part1: Nurses' socio demographic characteristics and children characteristics. Part2: nurses' knowledge level. II: Observation checklist to evaluate nurses' performance. III: Palliative Performance Scale to assess nurses' performance regarding application scale. IV: Resource Utilization Groups - Activities of Daily Living Scale to assess the level of functional dependence for providing palliative care. V: Pain scale to assess pain. **Results:** Most of the studied nurses had good knowledge towards SPC, but one third of them had training of palliative care, and most of them had competent practice towards SPC. There was significant relation between nurses' total knowledge and their total performance regarding SPC for oncology children. There were a significant relation between nurses' characteristics and their total performance regarding place of working, qualification and attained previous training program about palliative care ( $P < 0.05$ ). **Conclusion:** Most of the studied nurses have an good knowledge and majority of them have competent performance about standardized palliative care for oncology children. **Recommendations:** From finding of this study, it was recommended that educational programs and courses for nurses who work in pediatric oncology units about palliative care to update their knowledge, practice and attitude toward care of oncology children and their parents.

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**Keywords:** Standardized palliative care, nurse's performance, oncology children.

## Introduction

Childhood cancer occurs anywhere in the body, including the blood and lymph node system, brain and spinal cord Central Nervous System (CNS), kidneys, and other organs and tissues, begins when healthy cells change and grow out of control. In most types of cancer, these cells form a mass called a tumor. The diagnosis of cancer in children and adolescents is a life – altering event for them and their families. Although advances in treatment have increased the overall 5 years survival rate for childhood cancers to approximately 80%, cancer is still the second leading cause of death in children aged from 8-18 years old (*American Society of Clinical Oncology (ASCO), 2018*).

Oncology children experience physical, emotional, social, and spiritual suffering as a result of the disease process, treatments for the disease, and treatment-related side effects. Therefore standardize palliative care is necessary for oncology children as experience a high number of treatable symptoms that result in substantial suffering (*Feudtner et al., 2015*).

Palliative care for oncology children includes physical, psychological, educational, social, and spiritual goals and is provided concurrently with disease-modifying therapies or as the main goal of care. This care aims to enhance life, decrease suffering, optimize function, and provide opportunities for personal and spiritual growth, as palliative care is an approach that improves the quality of life of patients and their families (*Curcio, 2017*).

Worldwide, each year an estimated 40 million people are in need of palliative care, children constitutes 98% of those who need for

palliative care who's live in low- and middle-income countries (*World Health Organization (WHO), 2016*). In high-income countries, it has been estimated that 69–82% of those who die are in need for palliative care. Despite the enthusiasm for palliative care, recent data showed that only 14% of patient needing palliative care at the end of life received it (*National Hospice and Palliative Care Organization (NHPCO), 2016*).

Evaluation of performance for standardized palliative care begins with a clear and meaningful definition of its objectives, also be formative, continuous and providing the nurses with information on progress. As palliative care aims to make oncology children and their families as comfortable as possible by means of early identification, impeccable assessment and treatment of pain as well as other distress symptoms. Also provide them with psychological, social, spiritual and religious support as appropriate (*WHO, 2016*).

Standardized palliative care as specialized medical care follow standard care that benefits those suffering from chronic and/or terminal illnesses by placing priority on pain and symptom management to achieve optimal quality of life. By using a team approach to meet the needs of patients and families, as well as bereavement counseling (*Weaver et al., 2017*) and ensures that oncology children have a quality life over a quantity life (*Meier, 2015*).

So, the palliative care contains integrated multidisciplinary team includes physicians, nurses, psychologists, physiotherapists, clinical pharmacists, occupational therapists, dieticians, and social workers. In addition, pastoral care is also included according to the religious beliefs of the patient, collaboration between the patients, their

families, health professionals and the public toward a continuum of care confirming on physical, mental, social, spiritual and emotional dimensions of care for life-limiting or life-threatening conditions (*Gadallah, Hassan & Shargawy, 2017*).

The purpose of standardized palliative care for oncology children to deliver competent, compassionate, and consistent care to the child facing a life-limiting illness. However, palliative nurses are prepared to meet the standards of palliative nursing care, which include comfort, enhancing quality of life, decreasing suffering, optimizing function, effective communication, and providing opportunities for personal, developmental, and spiritual growth while respecting the culture of care setting (*Chow and Dahlin, 2018*).

Utilization of standardized practices in health care reduces variability, and increases interoperability, safety, repeatability. Thus improving quality. Also continuity of care throughout the disease trajectory and across the different settings in the healthcare system is a basic requirement of palliative care. As well as preventing crises and unnecessary transfers is an important outcome of palliative care (*Anghelescu et al., 2012*).

Palliative care is characterized by diversity of care delivery models; focus of care on effect of cancer on the family as the central; and consideration of culture, spirituality, communication, and ethical standards. End-of-life issues that anticipated by nurses and other clinicians include symptoms of cancer or its treatment, the importance of hopefulness, the relevance of trying to be a good parent in decision making, the meaning of legacy making of ill children and family bereavement (*Groh et al., 2014*).

Communication, planning and coordination of care are a fundamental component in standardized palliative care, an intervention that when optimally employed facilitate easing suffering and enhancing well-being. Palliative care introduced in several different settings: as a standalone service in a center or hospice, hospital-based, community-based, and home care (*Wolfe et al., 2018*).

Palliative oncologies nurses' are specialized professional nurses play a crucial role in providing care, support, and education to children as well as their families who have a variety of cancer diagnoses, serve as a consistent presence throughout the duration of their treatment. Their care should be directed towards following the therapeutic regimen to improve the quality of children's life. Moreover, provide parental support and education about the general principles of care for those children (*Hagmann et al., 2018*).

Standardized palliative care nurse has a basic knowledge and skill set as imperative to assist patients with the utmost care and compassion care for affirming life and regarding dying as a normal process; neither hastens nor postpones death; provides relief from pain and other distressing symptoms; integrates the psychological and spiritual aspects of care; offers a support system to help persons live as actively as possible until death; and offers a support system to help families cope during the child's illness and in the bereavement (*Dahlin, 2015*).

Palliative nurses are key members of the palliative care team and it is essential that they keep abreast of new treatment developments. So that their care reflects best practices. Best practices include safe administration of anti-neoplastic treatments (chemo biotherapy, surgery, and radiation), symptom control, survivorship,

rehabilitation, palliative and end-of-life care. Each cancer phase and subspecialty requires unique knowledge and skills. Furthermore, this care adapted to be provided in acute, ambulatory, and home care settings (*National Consensus Project for Quality Palliative Care, 2013*).

Respect for the dignity of patients and families, the provision of palliative care for children include sensitivity to and respect for the child's and family's wishes. In consultation with the child's parent or guardian, the plan of care incorporates respect for the terminally ill child's preferences concerning testing, monitoring, and treatment. Consistent with this principle of respect, information about palliative care readily available and parents choose to initiate a referral to a pediatric palliative care (*Alconero-Camareroa et al., 2018*).

Palliative nurse use inter professional process of communication and decision making that enables the separate , shared knowledge and skills of health care providers to synergistically influence the patient care provided ,and designed to promote the active participation of several health care disciplines and professions. It enhances patient, family, and community-centered goals and values, provides mechanisms for continuous communication among health care providers, optimizes staff participation in clinical decision making (within and across disciplines), and fosters respect for the contributions of all providers (*Horner and Nativio, 2019*) .

The advanced practice of standardized palliative nursing care's scope of practice includes improving quality of life by providing clinical expertise, pain and symptom management, continuous integrative and coordinated care across health care settings. Developing and evaluating the role of the advanced practice nurse in

standardized palliative care lead to improved patient outcomes and cost savings (*Guo, Jacelon and Marquard, 2012*)

Pain in oncology children caused by a number of factors as cancer mass itself produce pain by tissue distention or infiltration and inflammation due to infection, necrosis, or obstruction also cause pain. Cancer treatment consisting of chemotherapy, radiation therapy, and surgery cause pain so nurses accurately assess the child's pain and intervene appropriately; pain control is of paramount importance thus, benefit from palliative care early in their disease course (*Casellano-Tejedor et al., 2015*).

Standardized palliative care at end of life prevents unwanted or inappropriate life-sustaining measures during the final months of life and addresses the concerns of families regarding symptom management and emotional support (*Holland et al., 2018*).