

Unmet Needs of Children with Chronic Life Limiting Illnesses: Palliative Care Nursing: A Reflective Learning

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ABSTRACT

Context: Witnessing the chronic suffering of children with neuromuscular and other life-limiting illnesses is disheartening. A targeted and concentrated approach could enhance the quality of life for these children and their families, who are frequently overlooked by healthcare practitioners.

The goal: This practice of "reflective learning" aims to heighten the focus and awareness of the plight of these suffering children, emphasizing the critical necessity for a personalized and family-centered approach to their care.

Implications: This reflective experience underscores the significance of integrating palliative care education into the nursing curriculum, thereby empowering nurses with continuous education on palliative care and enhancing access to pediatric palliative care services for children and families.

Conclusion: Incorporating palliative care in the ongoing care of children with chronic suffering can improve the quality of life for all involved.

Keywords: Palliative care, reflective learning, holistic care, physical, psychosocial, and spiritual.

INTRODUCTION

Palliative care is a specialized health care approach that focuses on enhancing quality of life for patients with life limiting and life-threatening illnesses by addressing their physical, emotional, social and spiritual needs. It is a relatively new concept that has evolved across the world during the last few decades. Nevertheless, palliative care services are still inadequate in many parts of the world, especially in developing countries. The availability of palliative care services for children is poor, and there are misunderstandings and misconceptions

about the children's palliative care services. The limited services available are usually given to children with cancer, however, estimates from the global pediatric palliative care needs by disease groups indicates that cancer represents only 5.69% of the 11 need categories.¹

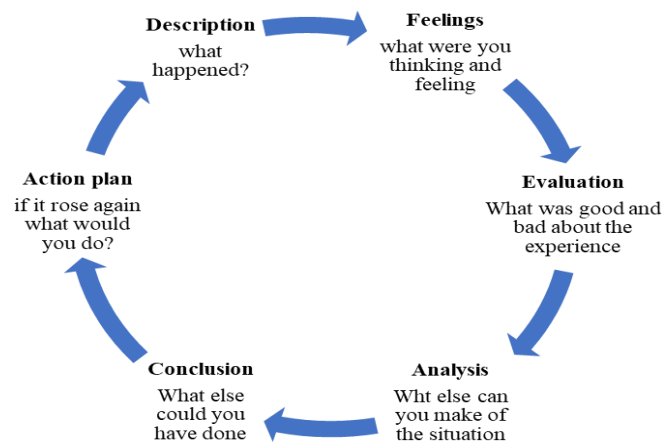
Whilst attending the 'Certificate Course in Essentials of Palliative Care' organized by Indian Association of Palliative Care (IAPC), I was inspired to look more closely at my personal experience of working with children suffering from Neuromuscular/neurodegenerative disorders. These

conditions fall under the broad category of children with Progressive conditions without curative treatment options, where treatment is exclusively palliative and often lasts for many years.¹

According to the University of Edinburgh, critical reflection involves the conscious examination of past experiences, thoughts, and actions. Its goal is to uncover insights about oneself and a situation to facilitate learning and implement changes in the present and future. Reflection challenges the status quo of practice, thoughts and assumptions and may therefore inform our decisions, actions, attitudes, beliefs and understanding about ourselves.² Reflective practice serves as an effective tool for nurses to steer their professional

development and apply insights gained as they strive to consistently deliver high-quality and safe care to patients each day.

There are several models that can be applied to structure this reflective practice. These models include the: 5R framework which includes Reporting, Responding, Relating, Reasoning, and Reconstructing by Bain et al. The four F's - Facts, Feelings, Findings, and Future model by Roger and Borton model with three simple questions - What? So what? Now what?³. Gibbs 'reflective cycle (1988) is one of the most famous cyclical models.² It is structured using six stages of exploring the experience: description, feelings, evaluation, analysis, conclusion, and action plan.



Adapted from Gibbs-reflective-cycle-model-1988

In this paper, I will use the six stages of Gibbs reflective cycle to structure my reflective learning experience of palliative care principles and practices.

DESCRIPTION (WHAT HAPPENED?)

The incident occurred while I served as a nurse educator in the Pediatric Intensive Care Unit (PICU) of a tertiary university hospital. I vividly recall three children who had been on mechanical ventilators for over four years, categorized as 'chronic' and 'known' patients. Each morning, we conducted the shift handover report at the nurse's station, but more often than not, we overlooked these three children, considering

them routine chronic patients during our visits and checks. One day, whilst changing the tracheostomy tie of baby X, the nurses noticed a stage two pressure ulcer under the tie. The unit manager and I were concerned this incident would impact the reputation of our nursing care unit. The nurses in the PICU were very knowledgeable and competent, the quality of care provided to acute critically ill children and recovery rate was good and often complemented by the management. We organized for the wound management and tracheostomy care team to intervene immediately, and within a few days the pressure ulcer started to heal.

Family support was also limited. In general, parents would stay in the hospital for a few days following the initial diagnosis. They then started to visit daily, then weekly, then monthly, then occasionally and then rarely. These patients were confined to life in an ICU bed looking at roof and watching monotonous videos and cartoons. What we had neglected to do from the start, was to establish a personalized holistic quality of life care plan for the patient, together with their family.

FEELINGS (WHAT WERE YOUR THOUGHTS AND FEELINGS)

Whenever we visited children who were confined to bed and on a mechanical ventilator for a very long time, our immediate reaction was “poor children.” We felt immense sadness and a deep sense of sympathy, but we failed to provide care with the empathy that was needed.

We justified the minimal care we were able to provide to these chronic patients by saying we were too busy and needed to pay attention to more acute critically ill children. Now, when I think back, I feel guilty for not focusing more on the children with life-limiting chronic diseases who were entrusted to the care of our nursing team.

EVALUATION (WHAT WAS GOOD AND BAD ABOUT THE SITUATION?)

What was good:

As a public hospital, any long-term ICU care was provided to these children free of charge. The hospital ICU was well equipped and had adequate facilities and resources.

There were exceptionally good and competent nurses in the unit. I remember one PICU nurse and a tracheostomy care nurse, gently talking and singing to the child whilst meticulously dressing the wound. I am sure this made the wound heal more quickly.

What was bad:

The unique and holistic needs of growing children with life-limiting illness were highly neglected. The children were simply labelled as chronic patients on long term

ventilator support, and we had a feeling that “nothing more could be done”. They received basic routine care, scheduled feeding, suctioning, changing diapers. This had even led to a case of physical suffering from a pressure ulcer.

ANALYSIS (WHAT ELSE CAN YOU LEARN FROM THE SITUATION)

This analysis stage looks at what and why things happened as they did. In my opinion, the focus on the quality of life for these children was neglected due to a number of reasons: a lack of awareness of how to integrate palliative care, inadequate training, an apathetic attitude, and a lack of an evidence-based assessments and care focus for children with life limiting neuromuscular disorders.

An article published in 2013 by the American Academy of Pediatrics on the Integration of Palliative Care into the Care of Children with Serious Illness, highlighted similar factors as those mentioned above. To address these issues and improve the care provided, pediatric health care clinicians should educate themselves, their patients, their practices, and their health care systems on the benefits of the early intervention of palliative care.⁴

CONCLUSION (WHAT ELSE COULD YOU HAVE DONE?)

Attending the ‘Essentials of Palliative Care’ course helped me appreciate and realize the importance of integrating palliative care into the care plan of children with chronic neuromuscular diseases, from the start.

Over the last three years, I have started to learn more about palliative care for children and gain insights into the different groups who can benefit from palliative care. Previously, my knowledge was limited to the field of palliative care in oncology, although we used to teach the importance of holistic and comprehensive care as part of the nursing process in all nursing courses. All the facilitators of the Essentials of Palliative Care’ course presented their own experiences and involvement with the

patients and families. This sparked within me a feeling of enlightenment, inspiration, and motivation to deeply look into this opportunity.

Following the insights gained from the course and extended literature search, I will now look at what I could have been done differently and what still be done differently for these children and their families going forward.

According to WHO, Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. It begins when the illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, emotional, social, and spiritual suffering.⁵

Physical Care

In retrospect, we should have visited these children every day during the handover shift and performed an assessment of their individual pain and suffering. With regular attention, the pressure ulcer could have been prevented and saved the child from unnecessary suffering.

The distress of children with tracheostomy and on a mechanical ventilator should have been addressed using any of the following examples identified by an expert consortium: frequent monitoring of pain and symptoms including joint and muscle pain, soothe discomfort associated with mobility and positioning, GI discomfort due to reflux, dyspnea and by optimizing interaction, mobility and positioning.⁶

Psychosocial and Spiritual Care

We could have arranged 'meaning-making' family activities to encourage parents and families to spend time with their children and create moments of connection. For example, taking pictures, family gatherings, celebrating milestones.⁴

We could also have reframed the definition of a 'normal' child for the families and encourage bonding behaviors and attitudes from family members⁴

I could have also been a role model by spending meaningful time with the children, and in this way encourage nurses who spent time engaging in appropriate developmental and playful activities, with special recognition.

Communication with the child and family

The nurses were very kind to the children and tried to talk to them, but that was not enough. The health care team members had a good communication with the family during visits, however we were not able to establish ongoing bonding and connection between the child and family. This resulted in infrequent family visits. We should have put an agreed plan in place from the start. To compensate for this lack of connection and interest from the families, a psychosocial support as mentioned above could have been helpful.

THE ACTION PLAN (IF IT HAPPENED AGAIN, WHAT WOULD YOU DO?)

According to Verma 'nothing more can be done', is one of the harshest phrases a patient and family can hear⁷. However, if we view a patient as a living, thinking, and feeling human being, there is always something that can be done. Palliative care emerges as the solution, as it not only facilitates peaceful end-of-life transitions but also supports individuals in maintaining their quality of life until their passing. While palliative care may not offer a cure for illness, it frequently contributes to a less painful and more meaningful life for patients throughout their remaining time.

Leading by example is often a powerful means of encouraging new behaviors. If each nurse makes a point of providing palliative care to these patients, this will eventually have a large- scale impact. The nursing faculty should integrate the holistic care approach into the clinical training curriculum. Student nurses in training

should learn to take care of these children and their families as a best practice when they graduate as nurses. By enhancing their approach to children and families in need of palliative care, teachers can play a pivotal role in motivating nursing students, who represent the future of nursing.

Ongoing training is an essential component. A strong connection with colleagues in the hospital's nursing education department is key in order to ensure that nurses receive ongoing training on palliative care. Until recently, palliative care was not included in the curriculum for most of the nursing schools. Ongoing education and on-the job training on palliative care should be standardized across all healthcare institutions.

Technology: is important on many levels. It can help anticipate the patients' therapeutic needs and be used to provide educational, and social support through the use of technology itself.

Ongoing Research should monitor progress and suggest improvements. The collaboration between nursing administrators, educators and practitioners should be systematic in order to carry out research projects and gain insights on the benefits of palliative care for children with chronic illness.

CONCLUSION

The collaborative efforts of a multidisciplinary healthcare team are crucial to improving the situation and empowering families to actively participate in defining, creating, and safeguarding a quality of life for children unfairly burdened with chronic, life-limiting illnesses. Through palliative care, we foster open communication and mutual respect among team members, ensuring comprehensive support and optimizing the well-being of these children and their families.

Declaration by Authors

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