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Palliative Care in the Neonatal Population

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Palliative Care in the Neonatal Population

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NURS-5382: Capstone

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Acknowledgments

I would like to thank the instructors who helped guide me in my educational journey. I started this journey with life in a flurry all around me. There were moments I was unsure if I could continue my quest to gain a graduate-level understanding of the nursing process and theories. Each step of the way, when I needed reassurance, every instructor was available to push me toward my goal of becoming a nurse practitioner. My experience in the neonatal intensive care unit drove my desire to proceed with this project. My goal has always been to provide the best care possible, no matter the circumstances.

Executive Summary

Neonatal and infant loss is common worldwide in neonatal intensive care units (NICU). Palliative care consists of improving the quality of life for the patient and their families while confronting the challenges associated with a life-limiting illness or complex medical conditions. The United Nations Children's Fund (2021) reports that globally, 2.4 million children died in the first month of life in 2019 – approximately 6,700 neonatal deaths daily. About a third of all neonatal deaths happen within the first day after birth, and close to three-quarters occur within the first week of life (United Nations Children's Fund, 2021). Such reports indicate why palliative care is an essential integrated, patient-centered health service. Relieving severe health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility (World Health Organization, n.d.). A holistic approach to nursing is an integral part of providing patient care. Neonatal intensive care nurses care for more than just the patient; they also care for the family members. When palliative care is available, expert pain and symptom management are recognized as augmenting the baby's and family's quality of life, even while cure-oriented or disease-modifying treatments are offered (Carter, 2018). Palliative care inhibits

and eases suffering through the early recognition and treatment of a patient's physical and psychological needs without causing further undue harm. Introducing palliative care to families of admitted infants shortly after admission will reduce distress and enhance the quality of life for such patients.

Project Rationale

Most organizations have protocols in place for bereavement care and withdrawal guidelines once a decision has been made to withdraw care. However, there is no protocol to introduce palliative care on admission even when the diagnosis is known to be grave, despite the fact that a house-wide palliative care team is available, but very rarely are they utilized in the NICU. Assessing and managing a patient's pain control, neurological symptoms, respiratory distress, nutrition, family/infant bonding, and the psychosocial distress of the family can improve the quality of life for these fragile children and their loved ones. There is a great need to standardize practices and obtain follow-up quality measures. Guidelines to address infants' basic needs and to achieve a state of comfort are what I am proposing. A multidisciplinary team specific to the unique needs of neonatal intensive care patients. If palliative care is declined, general quality improvements in complex care could still be possible. The introduction and implementation of palliative care in the NICU enhances consistency in patient care and reduces distress in an already traumatic situation. Switching from aggressive life-saving measures to comfort care allows for intimate contact between parents and their children, which is not always possible when undergoing intensive treatment. In the Dallas/Ft. Worth area, it is not unusual for a patient to be born at one hospital and inpatient in their NICU, then transferred to another organization for a higher level of care. When policies vary significantly between hospital organizations, increased distress and confusion can be experienced by the families. In the future,

this evidence-based approach to palliative care can then be distributed statewide, then nationwide.

The Centers for Disease Control (2022) reports that in 2020, 19,582 infant deaths occurred. Congenital anomalies, prematurity, cardiac and circulatory irregularities, infections, respiratory distress syndrome, and hemorrhage account for more than 50 % of neonatal deaths (CDC, 2022). If neonates die, in more than 90% of cases, their terminal comfort care is provided in a NICU (Soni et al., 2011). NICU patients experience a variety of painful procedures, causing emotional and physical distress throughout their hospitalizations to provide life-saving measures. In a Level IV NICU, painful procedures that a patient might experience to prolong life include intubation, venipunctures, central line insertions, nasogastric tube insertion, the insertion and removal of chest drains, placement of urinary catheters, lumbar punctures, multiple heel lances for frequent blood evaluations. Palliative care inhibits and eases suffering through the early recognition and treatment of a patient's physical and psychological needs without causing further undue harm. Introducing palliative care to families of admitted infants shortly after admission will reduce distress and enhance the quality of life for such patients. When palliative care is available, expert pain and symptom management are recognized as augmenting the baby's and family's quality of life, even while cure-oriented or disease-modifying treatments are offered (Carter, 2018). Withholding life-sustaining intervention in the NICU while ensuring a high quality of life can feel counterintuitive. However, palliative care is about providing a unique type of medical care while positively impacting their limited lifespan. A fundamental tenet of palliative care is to not deliberately hasten death but provide comfort and dignity to those with life-limiting diagnoses (World Health Organization, 2019). However, Sieg et al., (2019) determined that mitigating infants' pain and suffering with opiates for patients receiving

palliative care is in the infant's best interest if the intent behind their use is to alleviate pain and suffering.

Literature Synthesis

A systematic literature search was performed using keywords from the PICOT question to yield relevant search results and data. Families confronted with the death of their child must receive guidance and support from qualified providers throughout their hospital stay to decrease patient distress. How healthcare providers manage the care of a dying infant can profoundly affect parents' capacity to cope with the passing of their child. Communication can be improved with training, increasing provider confidence in breaching complex subjects and decreasing the family's discomfort (Bowen et al., 2020). Nurses who work in NICUs that support palliative care practice report more favorable experiences and are more likely to champion palliative care initiation (Chin et al., 2021). Beltran and Hamel (2020) concluded that healthcare providers' perspectives on neonatal palliative care with proper end-of-life care had disparities in producing consistent neonatal end-of-life care practices. Provider subjective attitudes, encounters, and training influence how or if palliative care is discussed and recommended to the family of an ill infant, exemplifying how inconsistencies in the management of end-of-life care can affect patient distress. Caitlin (2017) discovered that 100% of physicians and 98% of nurses that participated in a study believed that palliative care was appropriate for infants with lethal medical conditions. Richards et al. (2018) physicians consulted palliative care when a patient's demise was thought to be within a short time frame, with inconsistencies noted when some physicians felt capable of providing quality end-of-life care without palliative care involvement. With such discrepancies in end-of-life care, palliative care consultation is indicated to best support the family, as formal palliative care can provide oversight of the many areas that are part of quality end of life

(Baughcum et al., 2019). Maternal anxiety and depression levels were lower when palliative care intervention was introduced in a randomized trial by Hancock et al. (2019). Limiting painful procedures and providing comfort measures like family/infant bonding and warmth while maintaining nourishment, 35 families surveyed who had elected palliative care for their dying child reported that their child was treated with compassion in a positive setting despite being in the hospital (Parravicini et al., 2017). Parent's relationship with staff and bereavement support is a major factor in reported satisfaction of care (Baughcum et al., 2019).

Stakeholders

A healthcare stakeholder is defined as any person, group, or association who delivers, obtains, manages, controls, or provides healthcare reimbursements and can include, for example, patients, family or next of kin, healthcare professionals, managers, regulatory bodies, non-governmental organizations, municipalities, and regional authorities (Aase et al., 2020). The major stakeholders in the healthcare system are the patients. Ultimately, they are the ones most affected by care. The potential stakeholders that would be affected if this benchmark project was implemented would include neonatologists, advanced practice registered nurses (APRN), bedside nurses, child life specialists, respiratory therapists, social workers, nutritionists, and chaplain services. The physician and APRN's primary role would be to oversee the patient's overall care, provide education about the patient's disease process and progression, and initiate palliative care. The bedside nurse would provide patient care dictated by the families' goals to provide comfort care. The respiratory therapist would ensure the patient's respiratory status is addressed to reduce distress. Child life specialists reduce parental and extended family distress by assisting in memory-making. Social work can assist in finding the family's ongoing community support. A nutritionist will assist in analyzing and recommending nutritional support

based on patient needs or parent goals. Hospital chaplains can provide spiritual support to the patient and their families. Chaplains can also provide memorial recommendations.

Implementation

This Benchmark study aims to illustrate where there is a need for improved patient experiences. Just because the technical patient is an infant does not mean reducing parent grief and stress is not beneficial to the overall care of the infant. Even if a patient is in this world for only a limited time, should it not be in the most supportive environment possible? Initiating palliative care earlier can do just that. Developing a palliative care policy and care team involves many phases in the planning process. Five steps are required from the initial stages to the implementation of a palliative care policy. The initial step starts with identifying and locating level III/IV NICUs that do not currently have or utilize a formal palliative care process for their patients with complex medical needs or life-limiting illnesses. Permission would be needed from providers, the hospital ethics board, any house-wide palliative care team, and the unit director. This step should take an average of two-three weeks to complete.

The second step in this process is to identify the professional medical stakeholders, which would include neonatologists, advanced practice registered nurses, bedside nurses, child life specialists, respiratory therapists, social workers, nutritionists, and chaplain services. Keeping in mind that further stakeholders may be discovered during this stage of the process. This current project is NICU-specific and, therefore, will not include perinatal implementation. Including allies such as clinical nurse specialists, nurses experienced in end-of-life and providers who believe that redirection of care in medical care is necessary to decrease barriers. Providers' moral and ethical concerns on what constitutes quality of life and medical care versus comfort care can

decrease effective palliative care team development. This phase could take an average of two-three weeks to complete.

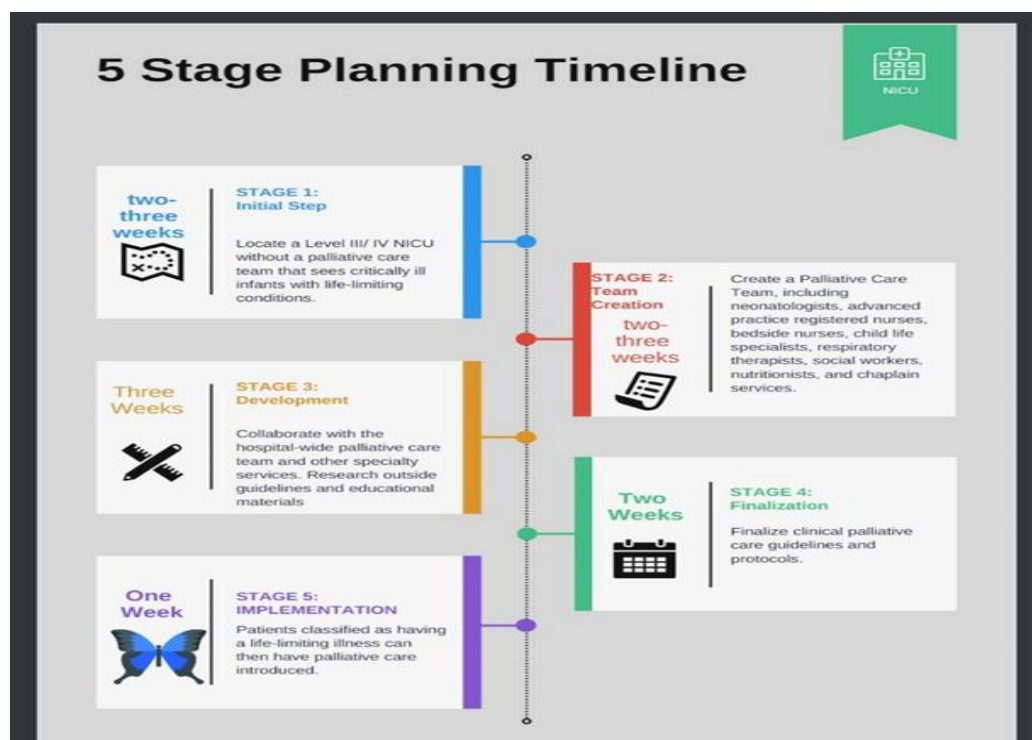
The third step in palliative care policy development is to collaborate with the internal house-wide palliative care team and garner their support and experiences in providing valuable palliative care to qualifying patients. Providing a greater understanding of the facilitators and the barriers they have experienced while providing palliative care within the organization. This phase includes gathering external data as well. Performing a review of the literature and collecting additional organizations' palliative care guidelines and policies as well as published palliative care guidelines to assemble the best level of evidence with the most up-to-date neonatal palliative care policies and procedures available. This third phase will hopefully take just three weeks but may require four weeks in total.

The fourth phase of developing a neonatal palliative care policy is to take all the gathered information and finalize the policy by determining what services provided are for the comfort and improvement of a patient's quality of life and which patient qualifies for the introduction of palliative care. The policy should be inclusive in a way that will have a far-reaching positive effect on both the patient and the family. The policy should aid in the transition to palliative care from curative medical care. This step should take two weeks to complete, with twice-weekly meetings that can be done via Zoom to facilitate availability for participation.

The fifth and final phase of developing a NICU-specific palliative care policy is the introduction of qualifying patients for palliative care. Monitoring of a patient's physiological status, comfort, signs of distress, and the family's physiological and psychosocial response and providing appropriate interventions would occur. The goal of decreasing daily pain scores, and

respiratory distress, providing nutrition, and overall comfort treatment modalities would be at the forefront of the palliative care policy.

Flowchart/Timetable



Data Collection/Methods

Initial measurement using the Neonatal Palliative Care Attitude Scale (NiPCAS) survey that includes attitudinal questions on a Likert scale among the palliative care staff would be completed. This would allow provider perceptions of the change to be evaluated before surveying affected families. Monitoring of the patient's physiological status, comfort, signs of distress, and the family's physiological and psychosocial response should be observed and collected. A family psychosocial response would be collected by the use of an open and closed question survey given weekly. Data on daily pain scores, respiratory assessments, heart rate, and comfort treatment modalities would be collected via the electronic medical record and assessed

against patients whose family's declined palliative. If proper palliative care could not be initiated, general quality improvements in end-of-life care could still be made, albeit in a lesser form and with less professional collaboration. If the project was implemented, evaluation would be completed by, The Stevens Star Model of Knowledge Transformation (Melnik &, Fineout-Overholt,2019, pp. 416-418) integrates scientific evidence with provider expertise and patient preferences. The model is built on the association between various sources, not just rigorous scientific evidence. This model works well to provide a framework of palliative care guidelines where no two patients are alike.

Benefit and Cost

Resources needed to enact change would include palliative care training for providers, nurses, nutrition services, respiratory therapists, social workers, child-life specialists, and chaplain services. Costs associated with this change would include educating staff and allowing scheduled time for additional education days and workshops. Additional costs could come from the educational program cost and material costs. However, by transitioning the level of care from curative to palliative, reimbursement by Medicaid and private insurance companies is likely to be collected as Medicaid and private insurance does not reimburse care costs once treatment is deemed futile. Receiving monetary reimbursement for provided care ensures organizational operating costs can continue to be profitable, as the average level IV NICU stay in the United States is \$8500.00 a day. For some patients, this cost can quickly add up to the millions. If the care is deemed futile and reimbursement of care is not received, that is millions of dollars that will never be recovered.

Discussion

The introduction and implementation of palliative care in the NICU enhances consistency in patient care and reduces distress in an already traumatic situation. Switching from aggressive life-saving measures to comfort care allows for intimate contact between parents and their children, which is not always possible when undergoing intensive treatment. The overall comfort of the infant and their family in a holistic manner is paramount to developing quality time together, no matter how short that might be. As this is a benchmark study, the success of this project is yet to be determined. If this project is implemented, the goal would be the introduction of the palliative care team to 100% of qualifying patients. The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (4th edition) (2019), a foundational document that defines the components of quality care for patients with serious illness, regardless of setting and applicable to clinicians in all specialties and disciplines can be used to assess overall outcomes. No one study can answer the question of rather or not involving the palliative care team earlier, as opposed to the latter, in the management of critically ill infants with life-limiting conditions affects the infant's comfort and quality of life. It is a complex issue involving many factors, as illustrated within this benchmark study.

Recommendations

Decreasing provider barriers to facilitating and implementing neonatal palliative care can be done in a few ways. Recommendations should be made for a study to be conducted with family members on why they chose palliative care so that facilitators to the parental agreement can be identified. This could help in the development of parental education on palliative care and decrease the negative association with it. The study should include multiple local organizations which have palliative teams available to participate. Using a set standard or interview questions to decrease variability would also be helpful. All professional medical providers that come into

contact with patients and their families should have their perspectives and education on palliative or end-of-life care analyzed. A palliative care team should be multidisciplinary. Current nursing school and Provider education, including more thorough end-of-life teaching, can only improve palliative care outcomes for fragile patients and their families. Palliative care in the neonatal population is not a new concept. However, it remains challenging to implement in a consistent manner, and many barriers still exist. Palliative care is fundamental in optimizing the quality of life and limiting the suffering of individuals with serious complex medical needs.

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