NewYork-Presbyterian Hospital

Alexandra Cohen Hospital for Women and Newborns

Neonatal Intensive Care

Care is revised to meet individual patient needs. This is a general guideline and is subject to change as new evidence arises.

TITLE

NICU Comfort Care Guidelines (Advance Care Plan)

PURPOSE

To serve as an adjunct to the NYP Policy OB 1529, NYP Policy D110 and NYP Policy PROC 119[1-3], and to standardize the interdisciplinary approach to comfort care, withdrawal of life-sustaining support, death and post-mortem care for patients in the NICU.

BACKGROUND

Palliative care can be defined as care that improves the quality of life of patients facing life-limiting conditions, and their families, through the prevention and relief of suffering, assessment and treatment of pain and other physical, psychosocial and spiritual issues.[4] There have been advances in pediatric palliative care following the publication of the American Academy of Pediatrics' guidelines in 2013, but implementation and utilization of neonatal palliative care interventions is low.[5] Studies have shown that palliative care interventions are used in only 13-24% of infant deaths.[6] Infants in the NICU are an especially vulnerable population, with most deaths occurring after a withdrawal of life sustaining support due to a life limiting diagnosis or imminent death despite maximum treatment efforts.[6] Despite how often comfort and palliative care services could be utilized, only about half of all NICUs in the United States have neonatal end-of-life or comfort care guidelines.[7-8] When perinatal palliative care programs are available, there is significant variability in services provided.[5] There is great opportunity for standardization of guidelines. Implementation of guidelines and education increases consistency in patient care, helping to optimize the end-of-life experience for both patients and families.[7] Neonatal comfort care guidelines should promote bonding, maintenance of body temperature, provision of nutrition/hydration when appropriate, and alleviation of discomfort and pain.[3] They should include palliative care order sets, discontinuation of painful procedures, memory making, care conferences/family meetings, and consultation of palliative care services.[9]

GUIDELINES

I. All aspects of NYP Policy D110, NYP Policy PROC 119 and “C. End of Life Care in the NICU” under “Special Considerations” in the NYP Policy OB 1529 remain true, with the following clarifications below.

II. Comfort Care Delivery Room Management of Patients with a Prenatally Diagnosed Life-Limiting Condition
    a. Inform NICU Charge Nurse. Inform multidisciplinary team including Delivery Room Attending, Delivery Room Fellow and Delivery Room NP for situational awareness, although a provider may not always attend these deliveries.
    b. NICU Charge Nurse to create an EMR group chat includes Child Life, Social Work, Pastoral and Spiritual Care, if not already done by the L&D staff.
    c. Pre-huddle, if possible.
        i. Clarify plans following family discussions regarding resuscitation attempts and plan of care for infant following delivery room management.
            1. If family would like to room-in with infant, care provided by NICU while on Labor and Delivery.
                a. When birthing parent moves to the postpartum floor, a virtual spot will be created in the NICU census and care will continue to be provided by the NICU team.
            2. If family does not want to room-in with infant, when birthing parent moves to the postpartum floor, infant will be transferred to the NICU.
    d. If infant survives past the delivery room and is added to the NICU census, either virtually or admitted directly to the unit, an Advanced Care Planning note must be documented by NICU attending.

III. “NICU Advance Care Plan” Order Set (see “Comfort Care Checklist”)
    a. Patient-dependent: cardiorespiratory monitoring, pulse oximetry, vitals (HR, RR and O2 saturation), newborn screen, intake and output, feeding plan, IV access and consults (consider PACT).
    b. Temperature at minimum Q12h, or PRN.
    c. If not on cardiorespiratory monitoring, consider q12h vitals (HR, RR and O2 saturation) to assess for pain or discomfort.
    d. No blood pressures, no daily weights and no weekly HC/length.
    e. No blood draws unless individualized for a specific condition.
    f. If newborn screen declined by caregivers, NICU attending to document in the EMR.

IV. When caregivers of infants undergoing comfort care or withdrawal of life-sustaining therapies are at the bedside, put monitor in “Comfort Profile” and ventilator in “Family View.”

V. Please refer to “Comfort Care Checklist” for memory making options.

VI. Purple Butterfly Initiative
    a. For any patients that have had a sibling loss this admission, are receiving comfort care, are in the process of withdrawal of life-sustaining therapies, are DNR/DNI, are high acuity with high potential for imminent death display the purple butterfly

outside of the room to alert clinical and non-clinical members of the team to the sensitive situation.

VII. Management for the Infant Receiving Comfort Care/Withdrawal of Life-Sustaining Support
    a. Assess pain and respond in accordance with NICU "Pain Clinical Practice Guideline"
    b. Non-pharmacological methods, as per the NYP Policy OB 1529 (see "Comfort Care Checklist").
    c. Pharmacological methods (see "Comfort Care Checklist")
        i. Morphine:
            1. IV (starting dose for opioid naïve patients): 0.01 mg/kg/hr continuous infusion - increase basal rate by 50-100% as needed, up to every 5-10 minutes. The IV formulation can be administered rectally.
                a. PRN (bolus from bag): 0.05-0.1 mg/kg q5-10 mins
                b. Rectally administered IV formulation dosing: 0.2-0.5 mg/kg q4h
            2. PO (starting dose for opioid naïve patients): 0.2-0.5 mg/kg q4h. The oral formulation can be given sublingually.
                a. PRN: same dose q1-2h
        ii. Fentanyl:
            1. IV (starting dose for opioid naïve patients): 1 mcg/kg/hr continuous infusion - increase basal rate by 50-100% as needed, up to every 5 minutes.
                a. PRN (bolus from bag): 1 mcg/kg q5min
                2. Intranasal: 2 mcg/kg q1h via mucosal atomizer device
        iii. Benzodiazepines
            1. To be used as second-line management of dyspnea

VIII. Considerations for Withdrawal / Withholding of Life-Sustaining Therapies (see "Comfort Care Checklist")
    a. If a patient is made DNI and is on a paralytic drug, consider discontinuation of paralytic drug. If an unintended ETT dislodgement occurs, administer neuromuscular blockade reversal.
    b. During regular hours, call Patient Services for approval of withdrawal or withholding of life-sustaining therapies. After hours, call the administrator on call (AOC) for approval of withdrawal or withholding of life-sustaining therapies
        i. This includes, but is not limited to: extubation, discontinuation of vasoactive medications and IV nutrition, allowing vasoactive/paralytic infusions to run out, not administering blood products, etc.
    b. Place an ACP (Advance Care Planning) note that includes the explanation of the clinical condition, diagnosis and prognosis. This must be attested by a PGY-4 or greater (and if time permits, should be a second NICU attending).
    c. Once approval is obtained:

i. Discontinue paralytic drugs and allow time for metabolism, consider neuromuscular blockade reversal.
ii. Consider discontinuation of vasopressors.
iii. Notify RT and wean ventilator settings prior to extubation, to allow for up-titration of medications to facilitate comfort.
iv. Consider removal or disconnection of tubes, drains or lines to facilitate holding. Allow family to determine what hardware remains in place, pending decision regarding autopsy.

IX. Death

a. Providers (see "Comfort Care Checklist")
    i. Physician or NP will pronounce the patient dead after 60 seconds of auscultation of the heart rate.
        a. If the patient is not undergoing withdrawal of life-sustaining therapy, suspend oscillation while maintaining mean airway pressure to auscultate HR.
    ii. Determine if caregivers want an autopsy – limited autopsy is an option (organ-specific). Consent form must be signed by family and be included in patient's chart when sent to Information Desk/Main Admitting. If family declines autopsy, document this decision in the "Death Note."
    iii. If caregivers are requesting public burial – consent form must be signed and included in patient's chart when sent to Information Desk/Main Admitting.
    iv. Provider to contact medical examiner + LiveOnNY.
        1. Infants > 36 weeks and > 6 pounds may be eligible for heart valve donation.
    v. First Contact Provider to complete hospital course + discharge summary in discharge navigator—discharge as deceased.
    vi. NICU Fellow to complete all other discharge navigator tabs.
    vii. NICU Fellow & Attending to co-sign "Death Note."
b. Nursing (see "Comfort Care Checklist")
    i. Notify unit clerk as soon as possible of patient death.
    ii. Complete "Fetal/Pediatrics Bereavement Checklist" flowsheet.
    ii. Complete "Nursing Note" as a free text that describes who was at the bedside, who declared the time of death and the memory making options and additional services that were offered to the family.
    iii. Provide post-mortem care, as described in NYP Policy PROC 119.
    iv. Of note, the family is able to accompany the infant to the morgue. If this is to occur, notify security. When request for transport is submitted, document that family will be accompanying. Personnel (other than transport) must accompany the family.

References

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